HIGHLAND USERS GROUP
HUG
ACTION FOR MENTAL HEALTH

Being Diagnosed with a Mental Illness

The views of 101 people on the impact and meaning of having a diagnosis of mental illness.

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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 343 members and 13 branches across the Highlands. HUG has been in existence now for 11 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.
- Challenging stigma and 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

Every year the HUG Round Table (our steering group) chooses a series of topics for discussion within our branches. This year one of the topics we chose to look at was the impact of being diagnosed with a mental illness.

For many of our members the very act of being diagnosed with a mental illness is hugely significant, with far reaching effects on our daily lives and the ways in which we view ourselves and how other people perceive us.

We were interested to see what the effects a diagnosis has upon us. Quite apart from the illness itself, we wanted to find out how we react and feel about it and whether we feel that it is useful to be given a diagnosis in the first place. We also wanted to know the difference between being labelled and being diagnosed and whether the very fact of receiving a diagnosis made us behave any differently.

We wondered whether different diagnoses had different social connotations and whether the words used to describe our various illnesses were helpful.

We discussed these subjects across our network in 2008 and involved a total of 101 people in the discussions. These conversations were recorded and formed into the following report which was then accepted by the HUG Round Table and then distributed in its present form.

What does a Diagnosis do to us?

Being given a diagnosis of a mental illness can be both a relief and a huge blow. It can settle our mind or make us very angry and it can have far reaching effects on our life:

The Positive Side to a Diagnosis - Reassurance and coming to terms with it

For many of us being diagnosed is a relief. It can help us understand what has been happening to us and, in addition, it can allow us to move on from a time of great uncertainty and confusion.

For many of us it is a point that allows us to consider the idea of recovery and the possibility of seeing our condition and life in positive, or at least more constructive, terms:

"*I had been trying to find out what was wrong with me for years. I wanted to put a name… to it. I could then look to the possibility of recovery.”*

It is also important that it is used as a point to gain information, ideas, coping strategies and messages which show us that although we may have a serious condition, it is not necessarily going to last forever or be severely incapacitating all the time.

"I'm glad because now I know what I'm dealing with. I can find out more about it. I can find out how to handle it and go on self management courses."

For many of us it is a point of relief and acceptance, when we finally have the chance to understand and have explained to us what is wrong, and why we are going through what we are experiencing. This can be a great step and a important breakthrough for us:

"*Relief; someone had sat down and told me what was wrong."*

It is also a point where we can reach out to others with similar experiences and realise that we are not completely alone with a confusing and alienating condition. Through this contact with others we can find ways of coming to terms and accepting what we are going through:

"At first I had no contact with anyone else with a mental illness. I felt on my own. Then I met others with a mental illness. That was one of the most positive of things."

It also explains to us our past actions and why we have done the things that we have done. Often we can be dismayed and ashamed of our past actions but when we finally understand that the things we have done have been rooted in an illness over which we have limited control, then we may find it easier to come to terms with ourselves and the past:

"…when you are diagnosed, I think a lot depends on the perspective. If you have insight it's ok but at first it's a shock. You can be in denial in way. But it can be a way of giving explanation to the crazy things that have been happening to you….It explained a lot of my past life and helped me understand the way I had acted the way I do."

It can be immensely reassuring and explain to us why we feel the way we do and allow us to gain comfort by coming to terms with having a condition that will inevitably have a major impact on our lives:

"…in a small way I am grateful. It has given me insight, perspectives others didn't have… Once I realised that I could move on and accept it without blaming myself."

Lastly, it provides access to the help and services that should hopefully help us and improve the lives we have which is something that many of us appreciate and are thankful for:

"…having a diagnosis puts you in the situation where you can get the right help and move forward…"

It Gives Access to Benefits

To many of us being given a formal diagnosis opens the gateway to the benefits system, and a life that is enhanced by a higher income than we were used to. The impact of some stability to our income and the opportunity to live with a higher income should not be underestimated:

"Getting a diagnosis gets us money; we may be eligible for disability living allowance."

It Has No Effect

Some of us found it important to say that the fact that we have been diagnosed has, in itself as an act of labelling, had little impact on our life or wellbeing but that in contrast the reality of our illness has a major effect:

"it's more the illness that causes the problems – jobs, housing, relationships, networks, social stuff."

It Opens the Way to Appropriate Treatment

For many of us there is a realisation that without a definite diagnosis, treatment remains uncertain whilst with a diagnosis we can be put on the proper medication and get other treatments appropriate to our condition:

"if they diagnose you then they know how to treat you and what sort of medication to give you."

"I was re-diagnosed from depression to bi-polar. It really helped as the anti-depressants were sending me high. So that stopped that and I got the right treatment. I'm happy with my diagnosis. It makes sense"

It Allows Us to Find Out More

Once we are diagnosed we can take a more active part in our treatment and care, by finding out more about our condition and learning ways of adapting to it:

“you can read up about it and this helps you understand it more”

It Allows Us to Accept What We Do

In a less positive way, being diagnosed can be comforting in that we can come to terms with what we have done in our lives as a result of our illness. There is sometimes something reassuring about being ill or even in feeling a victim of society or circumstance:

“being a victim is very comfy”

“for some people it’s quite nice, it gives them an excuse for bad behaviour.”

The Negatives of Being Diagnosed with a Mental Illness

There are a host of negatives that come along with a diagnosis of mental illness which range from facing the effects of stigma and discrimination to dealing with the pejorative labels some diagnoses convey to redefining yourself in negative ways.

Stigma and Discrimination

At the extreme we can lose our career as a result of a diagnosis of mental illness, we can face unhelpful attitudes and things like getting insurance or buying houses can become harder.

Work is something most of us aspire to, yet if we receive a diagnosis of mental illness we may lose our jobs, not be permitted to do some occupations, face fear at telling our employers or fellow employees our diagnosis or doubt that we any longer have the chance of a successful career path or even that we can get back into the job we used to be in.

“it has caused me to no longer be permitted to do the job I was trained to do and I have lost considerable earnings.”

Being diagnosed may mean that we lose friends and acquaintances and are viewed with suspicion by the community, which can extend to being called names in the street by children. This can lead to us withdrawing and stopping going out as we used to.

“I had a friend who I told I was schizophrenic, she never spoke to me again and stopped all contact. But I felt it was her loss.”

“… they hate me and wish I was out of the village, they see me as a thing.”

People may regard us in a new way, they may be suspicious of us or they may stop taking what we say seriously. They may be frightened of us and this is often a result of ignorance about our experience, especially from the public but also from professionals.

“when you are called mentally ill they look at you strangely; can I trust him? Will he flip out?”

Being diagnosed carried with it a host of preconceptions and ideas based around the terminology of mental illness and the attitudes associated with it. This gives rise to views about us based less on us as people and more on us as something defined by illness.

“It’s a label like you are placed in a category; it doesn’t aid our progress out of the illness because there is a stigma attached to it.”

People even make assumptions about our appearance, dress and demeanour once we are diagnosed with illness.

“there are stereotypes of what people with a mental illness look like.”

Even if we receive little stigma as a result of a diagnosis, the portrayal of us culturally, especially through the media, can have a big impact and be very damaging.

“*the portrayal of mental illness can be very bad.”*

And lastly in this section our own self image can be profoundly affected by a diagnosis and can cause us to feel like failures and lead to us losing confidence and energy.

“I felt I was no use to anyone at the time. I don’t feel this now.”

Family

Our family can be deeply affected by our diagnosis and may find it hard to come to terms with this new reality.

“my Mum doesn’t really understand; they reject the experience and don’t believe what I say”

However they may also be the route to our support and understanding because we cannot acknowledge our condition:

“I don’t recognise my illness; they have to rely on my family.”

However they may also challenge our assumptions:

“*my family won’t put up with me blaming the illness which is a good thing.”*

When it is Wrong

Many of our members commented on the confusion they faced through repeatedly being diagnosed with different conditions over the years. They often felt that this resulted in treatments which must, at some point, have been based on incorrect criteria and, therefore, believed that medication and other treatments may have been inappropriately prescribed to them.

“when you have a wrong diagnosis then you have the wrong treatment. You must have an accurate diagnosis. My diagnosis has changed many times.”

Being given the wrong diagnosis can have an effect on our overall health and sense of wellbeing and identity.

“it made me feel unwell [when] I was given the wrong one.”

It can also cause us to lose confidence and trust in the skills of the people that we have relied on to help and treat us.

“how do I know it’s accurate when they might re-diagnose me?”

On another level we may feel that our diagnosis is so vague that it is not only inaccurate but unhelpful.

“it can be hard to say what sort of schizophrenia it is.”

However some of us had an understanding of why a diagnosis might take time:

“sometimes It’s hard for the doctor to make an accurate diagnosis; it is understandable.”

The Effect of the diagnosis on our Self Image

Some diagnoses have a different impact to others, but almost all of us can be adversely affected as a result of the way in which we perceive our diagnosis.

This is especially the case with conditions such as personality disorder, which seem to carry a whole range of assumptions around it both held by professionals and the public.

"…being given a diagnosis of borderline personality disorder after some years. I asked what it was that was wrong with me. I thought he was being sarcastic to shut me up. The words were meaningless and offensive. I ignored it for some years. It is a dreadful word."

"I was told it was borderline in that it was borderline to psychosis but it feels like you are a borderline person."

The words can seem absolute or feel very negative which has a bad affect on our identity:

"*to be classed as mentally disabled – it's a negative spiral…"*

it can gives rise to a host of negative feelings that have a major impact on how we view our condition and ourselves:

"it's a horrible feeling; what's wrong with me."

In our efforts not to be affected by the diagnosis we may act in ways that try to assert our identity apart from the illness which we wouldn't have to do if it didn't have such a poor image.

"I try not to display symptoms and I go out of my way to prove that I am not ill but I can't do it."

It is Unhelpful because it's vague

A number of us felt that the diagnostic categories that applied were so broad as to be unhelpful in terms of appropriate treatment or self-definition:

"… but they are umbrella terms, not much use really [we] need help to understand that…"

"I was wondering if it is helpful to know. I feel it doesn't help me much, it's only words, it doesn't have meaning for my health. It may tell me about illness but it makes me more confused. It takes my attention from other things."

Its Influence on our Behaviour

The negative aspects of diagnosis can cause us to feel very awkward and embarrassed which may serve to make us hide from other people or feel very open to their scrutiny:

“I feel that being diagnosed can make you become more isolated. If you are asked what is wrong with you, if you say it to the person, you can feel inhibited. You can feel put on show.”

“when I am ill I can delve into it too much; read and read on it . I can start to take on an aspect of the illness.”

It Obscures the Problem

Some of us feel that a diagnosis can over medicalize what we are going through. Mental distress and mental health problems that disable us or lead onto mental illness can be caused by social factors just as much as by biological causes, and that this can stop the real issues that we need to address from being looked at properly:

“mental illness is not just a medical condition, it can be caused by society, housing, money, benefits etc”

Alternatively it prevents us from drawing our own conclusions and individual strategies for coping with our lives:

“I knew what was happening and was coping so well and was so proud of it. I both agreed with the diagnosis and completely dismissed it. I know I fit the criteria but I do reject mental illness. I don’t believe in it and feel its all down to a spiritual awakening and that if I had to agree that this was mental illness that this would have been very damaging. If I’d accepted it, in a lot of ways it would have made my life easier but then I wouldn’t have moved on.”

We don't want to know

For a variety of reasons we may not welcome being given the diagnosis and may resist it:

“I was better when I didn’t realise there was anything wrong with me. I had no idea there was anything wrong but they told me there was something wrong and now I don’t know what to do with it. I don’t know how to act and what would help me if I did know what to do.”

“you don’t know what is going on. When they told me what was wrong I went a hundred times worse. It’s too much to take in. they gabble on. You don’t want to read about it, you can’t take it in.”

We Don't Want to Conform to Treatment

Despite the fact that we may agree that we have an illness we may still not want the treatments and care that are offered to us:

“…what was a bit of a paradox was that I decided not to take the tablets.”

Alternatively we can become anxious about what might be done to us:

“I became frightened of what treatment they would give you, especially *if they section you.”*

The Past

The way in which we and our friends were treated in the past may have a big impact on our present thinking:

“I overdosed in the forties when it was a crime. I could have been sent to prison.”

“you have to remember that years ago it was different. In those days the outcome for schizophrenia was disastrous. I was told that I would end up as a vegetable on the back wards. I was told I would end up a cabbage. It was terrible for me I was in absolute denial. Now the outcome is much more varied.”

“I was put down for a lobotomy –it was terrifying but I managed to get away from it.”

How a Diagnosis Makes Us Feel

We obviously have a host of different feelings on being given a diagnosis the following is a reflection of the range of emotions we have gone through:

The Good Feelings

- Relief
- Back in control
- Now you can control your days
- More aware
- Acceptance

The Bad Feelings

- Furious
- Didn't understand
- Anger
- Frustration
- Very upset
- Very anxious
- Different
- Embarrassed
- Confused
- Bad
- A thorn in your side

What Are The Perceptions of Different Diagnoses - Are Some Better Than Others?

There are a wide variety of diagnoses, some with better social connotations than others. Although to some of our members any diagnosis can, by the fact that it is a mental illness diagnosis, be bad.

The following are the thoughts we had about different diagnoses both as reflection of our own beliefs and also of how we felt other people perceive them:

SCHIZOPHRENIA

This is one of the worst diagnoses and one of the hardest to be open about and is full of misconceptions such as people having split personalities.

“psycho in the headlines is associated with schizophrenia”

A few of us have a positive reaction to this illness:

“I like schizophrenia – it’s a soul thing”

BI POLAR

Many people feel that they can be open about this diagnosis now, and that in some ways it is almost a fashionable diagnosis to have.

Some people resent the recent publicity about it as they believe that “celebrities” have hi-jacked it and distorted how awful an illness it can be to have. Other people are glad of the increased awareness it has caused.
Some of us feel much happier to say that we are bi-polar but in the past would have felt bad and struggled to be open about the old word of manic depression.

Some people refer to it as the “genius” disease and also feel that it is associated with energy and creativity.

“Bi-polar is very hip at the moment”

PERSONALITY DISORDER

This is a diagnosis that many people struggle with and which most of us feel is a hard one to be given.

Some of us think that it can be an awful diagnosis but a few think that attitudes are beginning to change and that it is slowly becoming more accepted:

“Borderline Personality Disorder is getting more recognition but now attitudes are beginning to change. It used to be a terrible diagnosis.”

“Personality disorder: attention seeking, hypochondria. Not taken seriously. Violent”

PSYCHOTIC

There was a feeling that although this is a general term it is an unfortunate one and hard to deal with.

“psychosis - I’m proud of it. It’s a wonderful experience but people can be a bit freaked by it.”

“looking back I prefer schizophrenia as psychotic has an acute stamp… They’re both difficult sets of labels. I’ve learnt to cope with it over the years; you learn as you get older.”

EATING DISORDERS

Some of us felt that being open about eating disorders is harder than being open about psychosis but others felt that it was widely talked about. There was a feeling that it was almost always associated with anorexia and young women:

“anorexia is almost a commercial business”

“when I had it I never admitted to it”

DEPRESSION

This is one of the best understood and the least stigmatised conditions, but there are unhealthy reactions to it. These included people being protected from potentially stressful situations at work for fear it would stimulate a return of the condition and a worry that people oversimplify it and by relating it to their own times of sadness fail to understand how debilitating it can be.

There was a feeling that most people understood that it was possible to recover from this condition. A few thought that it was seen as quite a boring condition and some of us felt that because it was treated less seriously that people were seen as not deserving time off of work as a result of it or even that it wasn’t really an illness

“the most accepted is depression, everyone can relate to it in some way.”

ANXIETY

We felt that most people could understand this and that many people didn’t regard it as an illness. However because of this we worried that people saw it as not very valid or a sign of weakness.

OBSESSIVE COMPULSIVE DISORDER

We felt this was fairly well accepted but often treated in a light hearted and joking manner and that it is often not seen as an illness. Some of us felt that it must be an awful condition to experience.

STRESS

We felt there were a few labels attached to the word stress but that this could also mean that a person claiming to be stressed should be able to cope and pull themselves together.

POST TRAUMATIC STRESS DISORDER

We felt that this was much easier to understand and empathise with, and that it had less stigma than some other conditions.

Should We Change The Words That Describe Illness to Reduce Stigma?

Many of us felt that there was little point in changing the way in which we describe different disorders, as the key factor is the underlying attitudes that we face when such terms are used in a derogatory way. It is these issues of prejudice and lack of information that need to be challenged rather than the words themselves. Some of us felt that any word change would inevitably become its own new label.

However not all of us agreed with this. Some of the thoughts we had were as follows:

- Change the word “disorder” it is too negative and long term.
- Add some form of hope to a diagnosis
- Bi-polar coverage was very positive but has become slightly negative recently
- The word schizophrenia is very negative and may be better if it were changed to something else
- We should promote recovery along with diagnosis
- We should promote the strengths and advantages of people with a mental illness
- Borderline personality disorder could be changed if there were a more positive alternative
- We should make names of disorders understandable and descriptive as research throws new light on conditions
- The change from dementia praecox to schizophrenia was good and could be good with other terms

Do People View Us Differently When We Are Diagnosed?

Most of us agreed that this was the case, and that generally this change in attitude was negative however this did depend on the person, their relationship with us and their current knowledge.

“ if they are ignorant of mental illness then they do see us differently because they don’t understand.”

Some of us made the point that if people already knew us well and viewed us positively then this helped when they heard our diagnosis.

“…people don’t think that I am as capable as I am and I find this frustrating. It depends on what they know about the illness and what kind of people they are. If they know my life it may have more meaning for them, if someone understands the diagnosis they can be more helpful”

Some of us worried that we were seen as stupid, alternatively we felt we were not taken seriously and that we had a great need to keep up appearances which led us to talk of the need to continue to educate people about mental illness and provide accurate information as well as challenging stigma (as the ‘see me’ campaign is seen to do successfully as is HUG’s own anti stigma work).

Many of us had a great yearning to be accepted for who we are rather than being seen in terms of diagnosis. If we have other conditions or disabilities such as learning disabilities this could make life more complicated and attitudes are sometimes harder to deal with.

It is also difficult when the attitude of people such as GP’s change as a result of our diagnosis. Professionals may also find themselves considering only limited treatment options because of our diagnosis.

The negative influence of some of the media on those around us is not appreciated. However, closer to home, our families may see us as different and in small communities a reputation once established can be hard to shake off.

“My mum now treats me like a baby, watching me, wondering what I’m doing.”

Equally we may also change by finding a diagnosis comforting or even get into the habit of conforming to the expectations of those around us.

Can We Act Out Our Diagnosis?

Some of us agreed that we do sometimes act in ways that are determined by the fact that we have now been diagnosed although this is not always conscious.

"I got a lot of attention from services, the more attention I got the more I craved-leading to very attention seeking behaviour. In some way to get attention I would stop taking my medication to make the situation worse."

"I was self-harming on a locked ward, if I'd been on a normal ward I would have responded quicker but I felt "why not I've nothing to lose; that's why I'm here."

Sometimes illness and treatment brings its own comfort that can encourage us to maintain our illness. Sometimes the opposite occurs and we push ourselves too far once we have been diagnosed.
A few of us said that diagnosis reflected the importance of our own need to see ourselves as individuals and take responsibility for ourselves and others said that it can make us try to fit in more whilst others said that a diagnosis gives us a new identity.

It can also become something we are obsessed with; it can become addictive and take over our lives and is sometimes used to excuse our actions. Sometimes we can have a great desire to let everyone around us know the diagnosis though this is easier with some conditions than others. At other times we have a need to be with people who will share our road to recovery and may wish to be with people who promote work towards normality. Some of us felt that these strong feelings become less with the length of time in which we have been diagnosed.

"you fit in with the environment you're in."

However, many of us said that diagnosis on its own didn't account for much of our behaviour. Others said that being diagnosed can give us permission to be who we are and to become more content with the reality of our lives.

What is the Difference between a Diagnosis and a Label?

We had a lot of agreement on this, believing that a diagnosis is a medical statement and that labelling is the way in which society responds to that statement.

"diagnosis is information"

Labelling is usually negative, and is a tag attached to us which tends to define us, by illness or society's assumptions about the lives of people with illnesses such as ours rather than by seeing us as individuals.

“A label is given by anyone but it doesn’t recognise the person; it’s like being stereotyped.”

It is not just society that labels us we can also label ourselves as can professionals.

“the doctor said " you know that you will be on tablets for the rest of your life" but I lived free of tablets for five years. He said " you can’t work", did he mean now or forever?”

Some of us felt that some terms were also labels as well as being diagnoses. Because schizophrenia covers such a range of experiences we felt that it didn’t define instead it delivered a general label.

Some of us wanted to reclaim the pejorative words used about us such as “nutter” and show by doing this our pride in ourselves and our worlds.

“there is no difference. It’s who I am and it’s part of me, it makes no difference, I won’t be limited by it.”

How it Feels - Not Being Diagnosed

Many of us felt that not having a diagnosis was a great disadvantage. We found it frightening, confusing, frustrating, isolating annoying and stressful. If we didn’t have a diagnosis, it made us angry and made us feel persecuted and resentful and worried about what may be wrong with us. This could lead to us feeling worthless, assuming it was our fault and punishing ourselves. We found ourselves unable to learn strategies to cope and deal with our situation and help us look for recovery. We had a strong feeling that if we have been diagnosed then we should be told what this diagnosis is.

“for a long time (two or three years) I was told there was nothing wrong with me. I would go to hospital and the doctor said there was nothing wrong with me; it messed me up.”

“I didn’t know if I was mad or bad or understand why I was doing what I was doing. I felt very distressed, I just longed for a normal boring life.”

Some of us made the point that ideally diagnosis would be seen completely separately to the social consequences that occur with being labelled.

A diagnosis by its nature can also be the gateway to help and treatment.

“before I was going around looking for a cause, it was only when I got a diagnosis that I got a route to treatment and medication.”

By being diagnosed then we can seek out the peer support on offer from fellow users. It also provides an explanation that is easier to deal with:

"I spent years and years thinking it was my fault I was ill. Now I realise that it is genetic and not my fault."

THE ADVANTAGES

Despite usually wanting to know our diagnosis if possible, we were aware that it can be difficult to give a diagnosis and that giving an inaccurate and hasty diagnosis may be worse than having no diagnosis.

Equally there was a feeling amongst a few of us that a diagnosis automatically carried its own labelling and may be something that will inevitably cause damage to us. If we have a repeated change in diagnosis then we can become bewildered:

"I have changed from Attention Deficit Hyper Activity Disorder to Borderline Personality Disorder to Aspergers. I feel like I don't fit in anywhere. I don't know who I am, I feel even more like an outsider."

"I was diagnosed in half and hour. I am angry with the long list of labels."

It can also be something we don't like because mental illness is not acceptable or because we don't agree with our own particular diagnosis:

"good [not to have a diagnosis] if you have a learning disability and mental illness cos it often helps not to have a mental illness."

"I didn't like the diagnosis of hypo mania. I felt people would think I was a happy dafty and that everything I said was a heap of shite."

Not being diagnosed can also stop us from being seen as the same as everyone else with a similar illness, and may stop us from conforming to the stereotype of our illness. It may also be a good way of doctors being open and frank with us:

"if they explain why it will take time instead of just not telling us that might be a better way forward."

We may be unwilling to seek help for fear of what we will be diagnosed as having and may find a diagnosis unhelpful if there is nothing that seems to be able to be done to help. Equally it may prompt memories that damage us to remember.

"Be careful when diagnosing someone – can have real negative implications."

HOW MUCH INFORMATION ARE WE GIVEN?

The information we are given and the way in which we are given it can be critical in how we view what we are going through:

“I was prepared by my psychiatrist before the GP gave me the diagnosis. He prepared me in a very positive way.

“I got a pleasant surprise with my GP. He found out the circumstances around the trauma. Up here they didn’t understand but he did the best he could do. He found out for himself in order to help me. I’ll never forget that dedication.”

Ideally we would be given a diagnosis at an appropriate time and in a positive fashion.

Some of us are given very little information and resent this:

“I was given no information, I only found out by going to the library. I had to teach myself what the illness was.”

“I was diagnosed with paranoid schizophrenia in 2001. I felt relief that there was something wrong and that I wasn’t imagining it. Now they tell me that I am schizoaffective but they won’t tell me anymore. I ask and they skirt around it.”

“I was not diagnosed with a mental illness, I only found out my diagnosis by looking up to see what my drugs were prescribed for. It was really bad.”

“I only got information 8 years ago after 20 years of illness”

It is not just information about illness that we need but also information about services and risks and our rights. Ideally the person giving the information will be sensitive too so, for instance, if we are young we will be spoken to directly rather than via our parents. The form in which we are given information is also important:

“I didn’t mind being diagnosed but didn’t want to find out more.”

“we need a partnership, not the expert telling us what is wrong with us. Nowadays some doctors talk on our level. We are the experts in our illness.”

CONCLUSION

In summary the debate we have about diagnosis amongst ourselves reflects some of the debate that we find amongst different professionals and associations.

Most of us believe that there is such a thing as mental illness and that if we have such illnesses we have a right to know what it is rather than be protected from the damaging effects of a stigmatised label on our identity. A diagnosis is a formal way of putting a name to a particular condition; the fact that we are all human with a huge diversity of experience doesn’t mean that we have for this reason to resist definition. In some ways defining us according to impairment can be seen as a very negative way of viewing another human being and may make us distort our own vision of ourselves in very damaging ways. However it is a feature of our society that we tend to define label and characterise all forms of experience product and emotion. By defining the life we live and the things around us we make sense of our world and gain a greater understanding of what we are going through and what it is that surrounds us and makes up our world. Maybe in an ideal world we would all see the essential elements that give us a common identity and humanity rather than accentuating the things that make us appear different and maybe divide us from other people. For all of these reasons despite the negativity of a diagnosis of a mental illness the great majority of us think that it is something that should enhance our lives by helping us come to terms with and understand an experience that so often blights our life. Not being diagnosed can for some of us be much worse and much more confusing and offensive than being given a formal diagnosis that is hard to come to terms with. Without a diagnosis our fears can be increased our worry and confusion heightened and our self image and perception about what is happening to us may be greatly distorted.

However there is no doubt that a diagnosis doesn’t happen in a vacuum, what should perhaps be seen as a neutral medical term is always influenced by our society and culture. In the case of a mental illness this influence is almost always negative. The very fact that we have a diagnosis labels us as different and damaged. It causes other people to see us according to the broad stereotypes of a label as applied to a large group of people rather than as applied to us as people who still remain individuals despite facing adversity.

The effect of labelling leads to stigma, prejudice and discrimination, it causes poor self image, alienation and anger and distorts the way in which those around us react to us as people. This is not at all helpful and needs discouraged. In our view the best way of doing this is by public education and continued work to challenge negative attitudes and stigma. Although changing the way our illnesses are referred to may sometimes result in a shift in attitudes most of us feel that name changes will only ultimately lead to more labelling. What is needed is work that changes hearts and minds rather than cosmetic attempts to disguise a condition. Most of us would think that labelling would not stop if we were no longer given a diagnosis and that the effect of doing this would be more damaging than the reality of diagnosis.

We may be affected by labelling in many negative ways because society and culture and the people close to us react in new and perhaps hostile ways but we can also be affected because we are also influenced by it. We too, often share society's values about mental illness and sometimes may incorporate the negative attributes into our own self identity or even find ourselves conforming to our own internal stereotype of how we feel people with conditions like ours should behave.

Too often we are given poor or inadequate or even no information about our diagnosis. Helping us understand what is wrong with us is a hugely important process that can determine how we respond to treatment and how we view ourselves and behave in the future. We need to be told what is wrong in a sensitive and tactful manner with a realisation that it can be hard to take in everything all at once. We also need to know that when we are given what can be sometimes devastating information that this is done in as positive a manner as is possible and that our future is not wiped out in an instant and that the possibilities and ideas of recovery are incorporated into the messages that we are given.

A few of us are aware that there is a debate about the validity of diagnosis in any form. Some people still reject the idea of mental illness and others say that the different illnesses with which we are diagnosed represent such a range of varied conditions as to render diagnosis meaningless. Most of us have little information about this debate and therefore little comment to make. For some of us repeatedly being given a different diagnosis is highly confusing and echoes this debate often causing us to doubt the judgement of professionals and to wonder at the varied and different treatments that we have been given in the past when our condition if not its definition has remained relatively constant.

Lastly whilst the great majority of us believe in the need for diagnosis some of us would also say that diagnosis is only one way of seeing a particular experience. Our history upbringing, beliefs and culture all determine the ways in which we view our lives and experiences. These cultural and personal interpretations of what we go through also need to be recognised and respected as being as valid a way of making sense of and understanding our lives as a biological interpretation of our illness. This medicalisation of our lives can undoubtedly lead to treatment that helps us recover and understand life in a particular way but the way we respond in our own world is the route by which we make the decision of how to lead our lives in that context. The vast range of routes we take to come to terms with illness and respond to experience are as numerous as the number of people with an illness. Each route has validity and each personal interpretation needs to be respected.

Appendix 1

Effect of Diagnosis

For over 20 years I experienced episodes of depression, varying in severity and length. On a number of occasions I was treated in hospital as a voluntary patient, with medication and I suppose “respite” as the therapy. My husband viewed hospital as a safety net, particularly when I was feeling acutely suicidal. There were times when I was well for several years, needing no support and not taking any medication. There were other times when the depression just seemed to linger as an ever present cloud or fog that just refused to budge. I existed but did not really function. It was not living, but not quite being dead either. There were other occasions when I would rapidly come out of a period of depression and become quite elated. These were the times when I would describe myself as well. Some of my friends may have described me as manic, but I was used to being a person who is energetic, enthusiastic with a wide range of interests. Since childhood I have probably over estimated what I could in the time available......OK, you may know what (if any) illness I have, but I had accepted I had a probably genetic tendency to depression.

Towards the end of 2007, my psychiatrist who had been helping me for about 18 months undertook a detailed review of my psychiatric history, symptoms, and medication prescribed. We had previously had a debate about whether I was bipolar, but came to the conclusion that was not appropriate as I had only ever gone high when taking antidepressants and presumably not depressed. However, the review led to the conclusion that I was bipolar (3). I had stopped taking the antidepressants, which my husband had been fairly sure were not helping me, and my psychiatrist was happy that I took no medication at that time. I was delighted! No more pills which restricted my diet.....I could eat cheese and drink some red wine again! (I should have remembered at New Year a few weeks later that I occasionally get a migraine...) My psychiatrist gave me the names of some possible future medications, which he might prescribe if I became unwell (with some information about possible side effects). He also made reference to the Stephen Fry documentaries.

So what did I make of all this? As I said initially I was elated that I had permission to not take medication. At the same time I was confused about being bi-polar (whatever type). I remember going home and just sitting for a couple of hours thinking about what to me was a huge change. And sitting quietly for a couple of hours when I'm not depressed is not in character. It made me feel very angry. Why had I taken medication for years that wasn't and probably didn't help me? I'm not inarticulate, and I had got on well with my previous psychiatrist, as well as my current one. Did I not communicate my symptoms at various times in the past? Why did I feel a huge difference between being told I was bi-polar as opposed to being someone who has depression? They can both be hugely debilitating at times.

Along with the diagnosis, had come advice that certain types of anti-depressants would and others would not help me. And it has been the long spells of depression that have had a devastating effect on various aspects on my personal life. Was I or my husband not forceful enough to say that I was ill in the past? Or was I too reluctant to chance taking something different for fear of it making me feel worse and have horrid side effects? As someone with a scientific background, I find the apparent lack of really good research into medication extremely frustrating.

The bipolar diagnosis was left in no question when, I went really manic a few months later. At least I now have some understanding of “psychosis”. Despite not having an advance statement at the time, my psychiatrist did know which medication I really did not wish to have prescribed, although the alternative did not work. It may have contributed to a longer stay in hospital, but some of that I could down to my "pig-headedness".

Now I really appreciate the work that was done to unravel what may give me considerable problems at times. I think I'm more “stable” than I've been for years (hopefully not too boring!). Diagnosis must be difficult in a very unscientific science, especially as the person undertaking that task just sees a snapshot of us. However, I have also seen it as being devastating for someone who change in diagnosis may also be linked to a change in very long term medication and support which has been ingrained in the person’s life style. When that occurs, it would be helpful if there could be additional support so that the person and those close to them can come to terms with the new diagnosis and its consequences. There needs to be more information in accessible form and more education so that we can understand the progress being made in psychiatry, and how hopefully it may be to our benefit.

ACKNOWLEDGEMENTS

We hope that you have found this report interesting. If you wish to comment on it then that would be very welcome as we love to get as wide as possible a perspective on the work we do.

The people we need to acknowledge most of all are our members and other people with experience of mental ill health in the Highlands. Without their voice we couldn't do anything.

Then there are so many professionals who support us by listening to and enhancing our voice. Without the partnership of people in health, social care and education our message would be so much less effective.

So a big thank you to all those that support us and work alongside us. Long may it continue.

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