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HUG THURSDAY THINK IN
THOUGHTS ON PERSONALITY DISORDER

INTRODUCTION

In late May 2015 ten members of the HUG Thursday Think in met to discuss personality disorder and trauma and issues around the subject.
The following is a list of the issues and some solutions we see around personality disorder. It has been added to by other members and interested people who heard about our meeting.

We hope this and the possible action points could be used as the basis for discussion in future HUG meetings, with the personality disorder steering group, with the Highland trauma network and other parties.
Issues

Diagnosis

This is often misunderstood, and can cause great distress when people are given it. It can also cause judgemental attitudes from the public and professionals.

We are aware that Trauma and stress are often associated with personality disorder and some of us think that CPTSD or PTSD (complex) post traumatic stress disorder) is a better description of this condition.

We need a shift in attitude towards this diagnosis, both from professionals, the public and also ourselves when faced with it.

Some ways of doing this would be to:

- Change the name – some people prefer 'emotional intensity disorder'.
- Provide more media coverage about the reality of it.
- Provide more direct contact with the public to see people with a personality disorder in a new light.
- Provide more joint training for professionals.
- Develop a Change Fund bid for the Highland See Me Change group.

PROGNOSIS

It is still seen as 'incurable' by many people and as not a 'real condition' also as something that little can be done to help people with.
This negativity and judgement around the diagnosis can lead to a lack of hope or will to work with the condition.

"We need to know there is the possibility of recovery."

"You fear you will never get out of it."

"You need reassurance"

We need more positive and accurate information about personality disorder and need to give people the chance of seeing a better future as well as to challenge and come to terms with one of the most stigmatising labels there is in mental health circles. This includes public and patient education but also guidance for professionals when making and imparting a diagnosis.

ACCESS TO SAFE PLACES

People with this diagnosis can frequently experience crisis, self harm and suicide attempts.

They are regularly refused access to hospital even when seen as a high suicide risk but there is not provision of a safe place for them to go to and feel secure when in this place in their lives.

People frequently say that when they are in crisis they can need to be taken out of their home situation both for their own health and peace of mind but also the peace of mind of their friends, family and neighbours.

"There is a need for all of us whatever our diagnosis – when we are in places when we are not coping – we need a safe place to support us until we are well enough to go back home –it may be half an hour or a day a few days away –we do our best to be in control and to manage ourselves but sometimes we need safety."

"Over the last three months ; somewhere safe would have been immense for me – speaking to people one to one was really good – I was able to phone as much as I wanted but I needed removed – it affects communities – when I am visibly distressed and self-harming on the landing, it affects the community around me even when they are good to you."

"I was begging for a service – I got Braeside – Fortunately people knew me there."

We also feel that situations could be prevented from escalating if we got help before we reached crisis and that sometimes this help would involve giving us a safe environment to calm down and relax in.

Although there is a resistance to providing safe houses and safe time with people, the continuing efforts of the police and others to stop the use of Police Cells as places of safety may combine with the views HUG has expressed numerous times in its reports on what helps us in crisis.
Equally the Glasgow model of intervention which is based on the Middlesbrough one may be something that could be established in Highland for dealing with people when they come into contact with the police.

ADDICTION

Personality disorder is often connected with addiction, people need help in this area and good links between the two services.

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ACCESS TO TREATMENT

We worry that there are inadequate services to help people with personality disorder in Highland and that accessing help can take too long.

"It doesn't give you a gateway to treatment – there is no comprehensive service across Highland or in Inverness and no sure way of providing for recovery."

"Out of Inverness there is nowhere to go to."

For some of us one of the key barriers to accessing services is being believed and being listened to, not having the seriousness of our distress acknowledged or the trauma we have faced addressed can force us into trauma again.

Many of us think there are occasions when we need hospital, sometimes a break for a few hours is ideal but at other times we need a hospital environment where we can feel safe for a few days. On occasion we receive very negative treatment when we are admitted.

"I was admitted – at the ward round they said "What are you doing here? Why are you acting out? We don't need you in here?" And I was discharged."

We know that people make an assessment of the risk we are to ourselves or others when making decisions about our care but often feel that it does not reflect our own perception of risk and does not always end up in help or support even when we are seen as being at a high level of risk.

We need to focus on what it is about Hospital that we value (see the HUG report on this subject) and about the further development of community services across Highland.

RELATIONSHIPS

Many of us are lonely and isolated and struggle to maintain and establish friendships and relationships. This loneliness can further exacerbate our condition and lead to a great deal of intense unhappiness.

We need to help people gain the skills to maintain relationships and provide opportunities where people who struggle to communicate can feel safe and able to do so.

CAS coping and succeeding.

It is good that CAS exists – some people who have gone through it say it is good and some people who have gone through dislike it.

Some people have been assessed and told they are not ready for it.

We should continue to carry out regular reviews with services users about their feelings on the service.

TREATMENTS

There are no drug treatments though some of us get anti psychotics that calm things down We would like to see a wider range of treatments for us to access.

BEHAVIOUR

"When we flip we have no control of what we say or what we do – if it is a brain development function should we be responsible for what we do – but how should we be treated as a result – if bi polar people are not held responsible when they are high why are people with a personality disorder when they flip?"

We are aware of research that says that brain development in people subject to childhood trauma can lead to aggressive and challenging responses in adult hood when such people encounter stressfull situations.

This may explain the high number of prisoners with personality disorder and also makes us question the use of the justice system for behaviours over which people have limited or no control.

"You can lose all grasp of things."

We would encourage debate about how responsible people should be made to feel and be held for actions as a result of their condition.

DIFFERENTIAL ACCESS TO SERVICES

"*I recognise me in this but I am p.t.s.d. – my behaviour is the same as personality disorder but I got access to services straight away – while people with a personality disorder don't get services very quickly."*

We can be told that we are using the services too often

We can be told to be responsible when we are in crisis – to the extent that we are told we are responsible for our own safety; this can be hard to deal with

Some people feel that they get minimal or no help:

"I phoned in a melt down and they said that they would not help they said "Just go back to your doctor.""

"Feeling responsible – is the refrain people give us all the time. I now find that as I am being responsible myself but as a consequence I will not accept treatment locally."

People sometimes find the only way that they get access to services is via other agencies such as the police.

We need to examine whether people with personality disorder get equitable and effective help from services.

OTHER SERVICES

Community mental health services can be vital for many of us, drop in centres such as Cairdeas Cottage in Inverness provide and safe and accepting place for people to go to that can deal with a range of behaviours.
The fact that Cairdeas is closing and that there are limited opportunities to access such services across Highland is of great concern.

Many people need a sense of friendship, community and belonging.

We should ensure that we maintain those community hubs where people can gain a sense of community and 'family' that they don't have elsewhere.

POLICE

Contact with the police can be frequent, they tend to be very helpful and compassionate but on occasion their attitudes and response are not helpful.

Sometimes they need to use police cells to keep people safe. This is not acceptable but neither is leaving people to their own devises when suicidal.

The fact that the police can be very worried when they take people for New Craigs for assessment and the assessment is not to admit very distressed people can leave people including the police bewildered . it reveals there is a big gap in provision between hospital admission and community treatment.

Sometimes the police rely on friends and neighbours to help care for people who are thinking of self- harming, and perhaps drunk and suicidal, this does not seem to be an adequate way of dealing with extreme distress either for the person or for the carer who may have little idea about what to do.

"When I was picked up by the police they weren't going to put me in a cell they knew I shouldn't be alone and wouldn't allow me to be alone – they made me find someone who would care for me – It was not fair on anybody - they and I should have had help from the NHS."

"I now tend to have the police come out to lift me rather than get help."

We should establish a group involving patients, carers , the NHS and the Police to look at this issue.

JUSTICE SYSTEM

"Connection with criminal justice lets care services off the hook."

We worry that the courts and the prison system sometimes inappropriately deal with people with a personality disorder and that there may more humane and effective sources of help.

TRAUMA CONFERENCE –

We heard about a recent conference looking at new approaches including trauma therapy – a shift to say that instead of looking at symptoms and what is wrong we need to move to a trauma focussed service.

One person who has been through this trauma focussed approach says that she has found it to be extremely helpful.

"Trauma is frightening – they were stripping the layers out – all of this is removing the harmful shells and replacing them with protective shells until I am strong enough to look after and be looked after and deal with the trauma – when it is resolved we turn it into a story - it is incredibly helpful – it is very raw but I am coping better. I cry more but my fury is much smaller. Now I know more who to go to and use the right language."

We hear that they are developing working groups across Highland to look at this . It would be good to have people with direct experience to be involved in these.

INVOLVEMENT

We feel that it is critical that people with a personality disorder and their carers have a say in personality disorder services and trauma services.

We have been asked to get involved with the personality disorder steering group .

"We feel it has been going for 2 years now and we have had no feedback – we got to a level where we interviewing candidates – and then we were ditched when CAS started. We don't want to go back."

We need to work out how to make the steering group accessible to people with personality disorder

TREATMENT AND DISTANCE FROM HOME

"After treatment – I cannot even get home – I am too distressed."

Some people have to travel over 100 miles for therapy and find that when they have finished a session much of the gains treatment may have given them are taken away by the trauma of getting home again when memories and feelings are still very vivid.

People resent being given limited sessions for treatment, after having been through DBT or STEPPES people still need support and could benefit from support networks. People still feel the end of a therapy means that they are left alone again to cope as best they can.

"We don't want time restricted sessions , we need what we need when we need it with the aim that we can ultimately cope better."

"I went through all the assessments –it's all about talk and then you are left to deal with it."

We need services to extend beyond Inverness and to recognise that the condition can be long term and therefore that long term support is also needed.

RELATIONSHIPS WITH PROFESSIONAL S

We believe that often the relationship we have with the professional who treats us can be more important than the actual treatment we are offered.

"We only recover with the right relationship."

"There can be an attitude of us to them and them to us. We struggle and they do too: we sack them they sack us and are judgemental."

"Sometimes we need to change the worker."

"Sometimes we don't know how to accept help – it is a sign of weakness."

"Being asked by them what would help? can be given to us and we have no idea and no idea how to answer."

"It can take a long time for them to recognise the severity of the problem."

We all need some better understandings of how we can treat each other when in a therapeutic situation.

INFORMATION

We have a great deal of need for information about what is wrong with us and what can help us and what we can do about it ourselves and what support we can get.

"Knowing you are ill and knowing why we need help and getting help."

STIGMA

We feel that there is a great need to change the attitude of the people towards personality disorder, both among the public and among professionals.

PREVENTION

We believe that the development of personality disorders and CPTSD could be avoided to some extent with investment in early years services.

Both in support for families, in parenting skills and in other areas where young people are affected by the people around them and their environment.

GUILT

Many of us who have experienced trauma feel intense guilt about this and a lack of self worth. We often feel that what we experienced is not bad enough to warrant assistance. We need to look at ways of helping people recognise that they do deserve and need help.

Actions in addition to those mentioned.

Pass this account to other service users to see what to add to it

Then pass to the

- NHS
- HS
- Council
- Police

- Meet police liaison officer
- Get the information about personality disorder and treatments from the NHS
- Act with physical health services too.
- Provide more opportunities for people with a personality disorder to meet.
- Get Dr Tim Agnew or Mhairi Will to come to a HUG meeting
- Take the subject to branch meetings
- Maybe an open conference that would attract more people – with the media included
- Films of personal testimony – find out if they can be used.
- Create a list of places to go and get help.
- Link with other agencies across Scotland
- Need to delegate this activity to members
- Newsletter articles