PSYCHIATRIC HOSPITALS

The views of 73 members of HUG on psychiatric hospitals, what the hospitals should provide, whether or not we need them and what they are like.

FEBRUARY 2005

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WHAT IS HUG?

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

At present, HUG has approximately 305 members and 13 branches across the Highlands. HUG has been in existence now for 9 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 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 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 etc.
- 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 group and interested parties.
- To increase knowledge about resources treatments and rights for users.
- To promote co operation between agencies concerned with mental health.

THE REASONS FOR THIS REPORT

In the spring of 2004 we had discussions in 10 of our branches on the subject of New Craigs Psychiatric Hospital that so many of us have had to use.

In total, about 73 members of HUG were involved in this debate as well as a few workers within the mental health field. This report is a distillation of their views.

We looked at a number of principles and issues, such as why we need hospital, whether it is necessary and whether there are any alternatives to it, as well as looking at what the stay was like when we have been too ill to manage at home.

The reasons for doing this were two-fold:

1. We have already written reports on admission to and discharge from hospital and wanted to look at how we felt about our stay in New Craigs now that it is well established.
2. The closure of the old psychiatric hospitals started in the mid 1970s and bed numbers have been reducing steadily since. In New Craigs there have been attempts to reduce the beds that are left, on the principle that people prefer to be treated at home and that hospital services are very costly. Freeing up some of these resources would allow greatly improved community services which could treat more people.

We have always resisted proposals to close beds, feeling that we are now at a stage where we have reached the minimum number of hospital beds that can safely cater for our community, and in reaction to comments from members about how short hospital stays were becoming and how hard it was getting to be admitted when in crisis.

However with such an important issue we felt that it would be good to look at these principles from the perspective of as many of our members as we could; some of the very people the hospital was built to serve.

IS A PSYCHIATRIC HOSPITAL NECESSARY?

The overwhelming feeling of our members was that there will always be a need for a psychiatric hospital in the Highlands. We want beds available when we need them and worry that it is getting harder to be admitted to hospital.

There is a need for somewhere to go when we can no longer cope at home; somewhere to go where we can find sanctuary, peace and treatment.

A small number of us disagree. We find the concept of hospitals offensive and would like to see them shut down as soon as possible. They represent an old fashioned form of treatment that is sometimes very restrictive.

WOULD IT BE JUSTIFIED TO REDUCE HOSPITAL SERVICES IN ORDER TO INCREASE COMMUNITY SERVICES?

We had a range of views on this:

- There seems to be an assumption that with better community services hospital becomes unnecessary. We feel that we are all on a continuum of health and at the extreme of mental distress we can become so ill that we can no longer cope at home.
  In this situation we need access to hospital. We believe the assumption that home treatment is effective and always preferable is not always justified and feel that hospital remains an important part of our treatment. To put one option against the other is not fair.

- A reduction of hospital beds would deny a service to a group of people who desperately need it and mean that one group of people receive a service in preference to another group.
  We feel that there are many people in great need of improved community services but, equally, a substantial number of people need to spend some time in hospital. Neither group of people should have their needs neglected because the needs of other people are seen as more important.

- The population that needs community services includes people who have stays in hospital but is by no means just the same group of people. It includes a much broader constituency and, therefore, the argument that this process is just one of providing different, more modern, treatments is not valid. It is replacing a service one group of people need at times, with new services that a much wider group of people need and have historically been denied.
  In other words seeing hospital and community services as being on a set of scales where a reduction in one inevitably results in an equitable increase in the other is not valid. The two services are related but not on the same scale and both will be needed in the coming years.

- We felt that the history of funding for hospital services had been one of continual reduction and that resources for mental health were not a high priority. We worried that further reductions in hospital funding could not be sustained. There is a need for resources to be transferred to mental health, not necessarily from other health services but maybe from other budgets.

- We also felt that any savings in bed reductions would be less than anticipated – the whole hospital site is costly and a reduction in beds does not result in a proportionate reduction in costs, as management, capital and facilities costs remain the same.
  Despite this, the majority of us did agree that if there were a substantial increase in community services, and it was proved over a long period of time that hospital beds were lying vacant, then we would then agree with bed reductions. At present few services are available 24 hours a day across the Highlands and therefore a reduction in services would not be sensible.

- Some of us wanted to emphasis aspects to do with the symbolism of hospital. It is sometimes seen as an inappropriate place, set apart from normal life, where people lose hope and the will to move on. Ideally it should be avoided and alternatives provided, especially for young people who may need every opportunity to avoid getting sucked into what can be a very negative lifestyle.

Overall we supported the idea of balance; increase community provision as that is where most of us live and receive services, but retain beds because on occasion we need them. However if a reduction did not affect the quality of our treatment or adversely affect other people then it

might be justified. If, however, a shortage of beds was damaging to patients then it shouldn't happen.

We also wanted to make the point that hospital is a part of our whole world, that it is a part of the Highland community and needs to increase its links with the wider population.

We also felt that the wider Highland population would oppose any reductions. Some of them had little knowledge of how to help us when we were in distress and felt that if we were in hospital we would be safer even if we had less freedom.

Some of us felt there will ultimately be a need for a substantial increase in investment in mental health and hospital services. It is well known that mental illness is increasing (depression is forecast to become the second most common form of morbidity by the year 2010) which will also mean a need for increased services. Also as awareness of mental health improves and the stigma of illness decreases, we would guess that more people will feel comfortable about asking for help.

ARE THERE ANY ALTERNATIVES TO HOSPITAL?

Many of us felt that there was no alternative. Hospital does provide a specific function that can't be replaced. However some of us did think that there could be options that would reduce the need for hospital. These included:

- Smaller homely community based units where people could relax and find peace and ways to cope with or get out of the situation they are in.
- A really nice warm atmospheric house where we can support each other and get support in turn.

Although it was partly a joke, people wanted to emphasis how expensive a stay in hospital is. Perhaps if we stayed in a nice hotel with support being provided as needed we would do much better and recover quicker! If there were safe houses or places of safety that we could use, these could also be used instead of hospital. These would have to be adapted to rural areas and we would need to be sure people didn't feel isolated in them.

Access to places where good quality free respite care can be obtained would also stop the, sometimes inappropriate, need for a hospital bed and may help people in a socially derived crisis.

Local hospital beds could also be good as long as they are adapted to the needs of people with a mental illness both in their staffing and environment. We also need a series of havens throughout the community available to anyone who feels they need them.

A dedicated Detox unit may relieve the pressure on New Craigs and perhaps defuse some of the tension between the two client groups.

Maybe there should be a separate mother and baby unit or perhaps postnatal illness can become seen as a natural part of childbirth and be routinely dealt with in a general hospital.

We can "need a place to stop and just be stopped in". "Somewhere peaceful and attractive where we can look at our emotions and have time out for relaxation." (HUG member)

WHAT WOULD REDUCE THE NEED FOR HOSPITAL BEDS OR COULD BE PROVIDED ELSEWHERE?

We do agree that eventually there may be less need for hospital beds if community facilities were greatly improved.
HUG has written many reports on what may help us in the community. Current issues in Mental Health (2002) gives a broad overview of what we think would help us locally.

Some of the things we mentioned this time were:

- Some therapies may be more accessible and effective away from a clinical environment.
- Out-patients could be better in the community.
- We need more access to psychological/talking treatments in the community.
- More occupational therapy could be good in the community.
- Basic knowledge of treatments and local facilities could be very helpful.
- Assertive and intensive treatment at home or home support can make a big difference. This may need to be 7 days a week.
- Crisis intervention would be helpful; somewhere to phone and go when in crisis.
- Access to a variety of activities such as relaxation and other therapies.
- A half-way house could prevent re-admission and help people get back home.
- More preventative actions.
- Somewhere to go at the weekends.
- Access to more social support.
- Sometimes we need space away from home where we can find peace and sanctuary and relaxation but this doesn't always have to be in a hospital.
- Access to support groups and self-help and self-management techniques as well as exposure to people who have recovered.
- Access to services provided by such projects as Befrienders Highland.

WHO SHOULD HOSPITAL BE FOR?

Although we agreed that hospital was principally for those with a mental illness many of us didn't think that admission should rest purely on a label.

The need for a place to feel safe in and get back to a state where we can face life again applies to anyone whose distress has reached a point where they can no longer cope, whether they are ill or not.

If someone can no longer cope emotionally or is self-harming then hospital should be seen as a potential option especially if there are no other safe places to go to.

We did agree that the decision should rest with a doctor, but equally many of us felt that if we could self refer to hospital or a similar facility when we can no longer cope, then that would be good.

We worried about people who are often very sad and even disturbed and yet are not seen as ill. Surely they need some sort of facility too? At present it feels that they are placed in a gap between services.

However, these facilities need to be able to respond to those in the greatest need especially those at danger to themselves or others.

WHO SHOULDN'T IT BE FOR?

- People the hospital can't help without putting other people at risk.
- People for whom admission has turned into a habit.
- People who are not wishing to get well but have different motivations such as keeping out of prison.

WHY DO WE NEED HOSPITAL?

We had many reasons about why we need help within hospital and these are as follows:

- Because we are no longer safe at home and need an alternative.
- Because we need more intensive treatment than we can get in the community.
- Because general services can't help us and we need access to specialist staff.
- We can be in contact with other people in similar situations.
- Because we are ill.
- Because there are little or no services where we live.
- Because we are a risk to ourselves or others.
- Because we are in, or getting into, crisis.
- Because if we have a break now then we won't get into a worse state.
- Because our family can no longer cope and relationships are breaking down.
- Because things have occurred that we can't cope with and which are affecting our health.
- Because we are changing medication.
- In order to be assessed.
- In order that we can be helped to see the scale of the problem.
- Because we need sanctuary.
- A place to get our thoughts and perspectives sorted out, to find solutions and regain motivation.
- A place where we can relax and feel safe in.
- A place where we can release emotions that would not be accepted in the community.
- To avoid self-harm becoming unmanageable.
- A place for when we cannot cope with ordinary tasks anymore.
- A place where we can reflect on life and where we are going.
- Some of us are so disabled by illness that we will need long-term help in hospital.
- Because community services are too busy or cannot provide enough support.
- Because we need space to stop being responsible, for instance as a mother or a wife and can be ourselves.

Mainly this means that there are times when we can no longer cope at home and need access to a place where we feel safe and can get the help we need to recuperate, recover and face life again.

Sometimes we just need time out and a chance to be away from the pressure of life, at other times we need intensive treatment and assessment to keep us, or maybe other people, safe and to help determine the best treatment for us when we return home.

AND WHAT IT'S REALLY LIKE

This section deals with the variety of thoughts that we had about New Craigs, both positive and negative as well as ways in which it could be improved.

WHAT WE GET FROM AN ADMISSION TO HOSPITAL

There are a number of things that we gain from admission to hospital and these include:

- Acknowledgement of our situation and problems.
- Care and support.
- Access to medication and some talking therapies.
- Access to people familiar with the sort of situation we are in.
- People who reach out to us and are not overly swayed by theories, dogma and concepts.
- Access to a pleasant environment with well-organised buildings and nice rooms and showers.
- Rest and peace of mind.
- Breathing space in a safe place providing sanctuary.
- Intensive support when needed.
- One to one sessions.
- Access to therapies such as anxiety management and relaxation, which can be very good.
- Access to expertise – for instance from the pharmacist.
- New friendships and people in similar situations
- Empathy.
- Access to nurses with the skills and knowledge to provide support.
- 24 hour care.
- Protection, respite and a rest for the family.
- A chance to get away from the home situation.
- Access to relief; somewhere to be looked after and to recuperate in, free from everyday worries.
- A place to calm down in.
- A chance to regain health and review our situation.
- Freedom from having to explain ourselves.
- A place to regain trust.
- A chance to socialise.
- Access to assessment and diagnosis.

THE GOOD BITS OF HOSPITAL

Apart from the list above, a number of other things were also mentioned:

Diagnosis

Getting a diagnosis can help throw light on our past experiences, which helps us accept the stage we have reached. For some of us, this can feel like being taken out of a void that we had become trapped in.

Some people feel that professionals are reluctant to give us a diagnosis, as each diagnosis has its own labels. The feeling about this was that this was a slightly patronising concept where we are not trusted with the truth. Hospital can be a place where we are finally told what is wrong with us.

Safety

Hospital is, for some, a place that represents safety and asylum and a way of escaping from the pressures of the world, where we can relax and receive help with our problems. It can be a refuge from an unbearable world.

The feeling of sanctuary is vital for some of us but equally we are aware that this refuge can become very attractive and may prevent us from returning to the outside world; hospital can become a cocoon.

The Environment

For many of us the new hospital, New Craigs, is a great improvement on Craig Dunain; it's very modern and comfortable.

Having our own rooms is greatly appreciated, as is the fact that there are rooms to meet other people in. Whilst some of us appreciated and missed the bustle of Craig Dunain many of us praised the fact that we could find a place to be on our own when we want to be. The overall design and layout also feels much better.

Some of us find the hospital to be comfortable, calming, silent and peaceful - a great space to be alone in. The fact that it is still relatively distant from the wider community and the city is also appreciated. It feels much less threatening than Craig Dunain.

The Nurses (and others)
They can be great; some are brilliant. (*"very nice and very good")* They are there to speak to when people need them and are encouraging and help out all the time. They are often very dedicated and very professional.
They notice when people need time and provide it.

"*We sometimes have access to fantastic named nurses, they can be the business, they help us with medication, give us one–to–one's in our rooms and room to talk privately. They also liase with and help advocate with doctors."*

"*The staff are amazing."*

Self harm
Attitudes here have changed for the better and this action is seen much less judgementally. Some of us say that despite continuing to self-harm we were made to feel safe and secure and were treated with great empathy by the staff.

Prevention
One person was told that a bed was available and that if he decided that he needed it then he just needed to phone up and an admission would be arranged. This provided a great sense of reassurance and safety. Just knowing that if admission is necessary then it will occur, feels very good and provides great peace of mind.

Recuperation
Some of us felt that we stayed in hospital slightly longer than was essential but far from resenting this found the chance to recuperate and regain energy very valuable.

The fact that meals were provided and we don't have to do everyday tasks when poorly is appreciated.

Access to the Café and Entrance Area
For some of us having access to the café and entrance area of the hospital is very much appreciated. It is a place to meet in and socialise.

Access to the City and Trips out

Being able to get to the city relatively easily is much appreciated. Some of us have gone on trips out of the hospital for the day. The chance to get out for the day, with support, can "*feel like heaven."*

It feels like there are more opportunities and activities such as this being made available in the hospital.

Activity

There are often activities going on such as occupational therapy, sport, and other therapies. These are much appreciated.

Community Connections

Some people praised the fact that staff assisted and encouraged people to keep up their community connections and activities despite being in hospital. This felt very positive.

Pass

The pass system and a gradual return to home is very reassuring.

Rehabilitation

Getting the chance to re-learn everyday skills and to be able to function in the community again is very helpful and very important.

THE BITS WE DIDN'T LIKE

Whilst the vast majority of our members saw the need for (and benefits) that hospital can provide not everything about hospital is good.

Sometimes this is because of differences of opinion about treatment or the purpose of hospital and sometimes because of the actions of staff and routines in the building.

The following are the feelings HUG members had about hospital when we met in 2004. Whilst it may be hard reading for staff we do hope that they can be taken in the constructive spirit they were meant to be made with.

Access to talking therapies
There was a feeling that there were not enough talking therapies or psychologists available in the hospital and that this was made worse by the incredibly long waiting list people faced on discharge.

Clinical atmosphere
The atmosphere was sometimes felt to be too clinical and lacked some of the camaraderie that could be found in Craig Dunain. Ideally the place would feel more relaxed and homely and informal.

The car park
This stretches right round the front of the hospital – it is ugly and off-putting.

The grounds
When the hospital was being built we were given assurances that landscaping would take place and whilst some has occurred, it doesn't make up in any way for the old hospital with its character, beautiful grounds and places to walk in, in peace.

The pink café
The old pink café in Craig Dunain which was a café used mainly by patients and sometimes staffed by ex-patients was cherished. It provided a place to be with each other which was relaxed and informal and separate to the hospital. The lack of a replacement is regretted.

Access to staff
It can be very hard to get to see nursing staff. They often seem to be 'stuck' in the nursing station rather than on the ward. It can be even harder to see a psychiatrist and almost impossible to see a psychologist.

Attitudes
Some staff seem to have preconceived ideas about the likely experiences that we will have had, depending on our class and education. This stereotype about people which is divorced from reality can be hard to cope with.

Sometimes staff seem to take a dislike to some of us which can be very hard to deal with. This can be especially difficult after a long stay or if we have been sectioned.

Sometimes it feels as though some staff are hard to get on with or are abrupt and ignore us and leave us to our own devices. It can be very hard to find someone to talk to outside of scheduled times. Sometimes we are not confident enough to approach nurses directly and this is not noticed.

If we don't get on with our primary nurse this can be difficult. Ideally action would be taken to change the nurse if there was some form of personality conflict.

When we are feeling bad about ourselves we may be very sensitive to negative attitudes from staff which can reinforce all our worries.

Some of us feel that we are pressurised to get involved in activities before we are ready and occasionally that we are not listened to and just told what to do.

Occasionally some staff can seem to be overbearing and patronising.

Smoking rooms

Many of us smoke in the hospital. The smoking rooms are small and invariably crowded. It does not seem sensible that so many of us have to crowd into the smallest space on the ward. Ideally these rooms would be more attractive, bigger and better ventilated.

Equally we do need to ensure we are not unwillingly exposed to smoke and that measures are put into place to help with the high rate of smoking amongst those of us with a mental illness (although not necessarily over the time of a hospital stay.)

Some non-smokers feel very excluded – they can't go in the smoke room and are left alone on the main ward.

(See the HUG response to second-hand smoke for more information.)

Young people

The hospital is not always the ideal environment for younger people. They may not feel that they fit in and can find it hard to ask for help. Sometimes it feels as though they are left to their own devices by some staff.

Single rooms
Whilst many people appreciate the single rooms, they can be places where people isolate themselves and retreat from everyone else. They are also areas where it is easy to self-harm. They can be lonely places to be in. Some people would like to see help alarms in the rooms – occasionally a person may be at great risk but unable to ask for help.

Stigma
There is still a stigma to a psychiatric hospital, which puts us off of the whole idea of admission.

Many people are ignorant of hospital and have outdated images of the environment and treatment. This can make us very apprehensive when admission is being considered.

Being ignored
Some us feel that we seek to help ourselves and to get encouragement to find a way out of our situation but instead of being supported in this feel as though we are pushed away.

Weekends
There is a feeling that at weekends everything starts to wind down. This also happens in the evenings. We would like to look forward to the weekend rather than dreading it. Many people hate being admitted on a Friday. We end up bored and frustrated with nothing to do.

The bands and socials that were a frequent and regular occurrence at Craig Dunain are greatly missed.

Other patients
Some of us feel open to abuse from other patients. There is a need for reassurance and demonstration that we are safe.

Abuse
Some of us are in hospital because of a history of abuse which has caused us great damage.

When we become aware that sometimes there are other patients around who have actually perpetrated abuse, any feelings of safety and sanctuary can disappear.

Visitors

It doesn't always seem as if visitors are welcomed. We talked about walking down to the nurses' station and being stared at as we approached but with no action being taken to greet us or acknowledge us.

Distress and behaviour

Some of us can get very upset whilst in hospital and act angrily. It feels that staff do not always appreciate the reasons for our anger.

Leaving early

Some of us are not happy with the care we get and leave. We may be leaving well before we should do.

Ward rounds

These can be hard to cope with. We often don't understand what is being said and find it hard to participate or ask questions.

(See the HUG report on Ward Rounds)

Rules and restrictions

Some of the 'rules' of the hospital are not appreciated, such as being frowned on for getting up at night or sometimes not being able to get a cup of tea.

In hospital we may feel worried about the lack of power and control we have. Actions by staff which reinforce these fears can be offensive to some of us.

Insensitivity

When patients, and very rarely staff, do things like ordering 'take aways' and then eat them in front of patients who can't afford to do this, then some of us can be offended.

Illegal drugs

The use of illegal drugs and alcohol in hospital is not at all good and causes great anxiety and anger to many of us.

However the previous zero tolerance policy also seemed too rigid when applied to those of us who have both drug or alcohol problems as well as mental health problems.

Some of us who have addictions face even more stigma.
Some of us think that people with addiction problems should have treatment but in a separate place to the main building.

Information

Some of us feel that we get almost no feedback about our illness from either doctors or nurses.

"They may listen and turn away; they are just ears. Do they listen at all? Are they qualified to listen?"

"No one told me about the illness or explained it to me. I only found out by going on to the internet."

Coping strategies

Some of us want to take an active part in our treatment. We want to research our illness, perhaps on the internet and want practical help with dealing with our symptoms. Sometimes we don't feel that we get this:

"How do I cope with my delusions and don't just sit explaining myself to myself."

"We need tips about how to deal with and cope with illness and why illness does what it does. We need help with symptoms and paranoia."

The atmosphere

Some of us do not like the atmosphere at the hospital:

"T*here is a lack of optimism."*
"There does not seem to be the attitude that we can get better."
"Hospital signifies change and it needs to signify new hope. It should not be like it is; we need to fill it with hope."
" We need to feel that we are going somewhere to be cured instead of trundled through."
"You need your life to be your life. We don't want illness emphasised."
"It can be quite violent and frightening in hospital"
"It can be a place where you can't breathe. You can be surrounded by people misusing drugs. It is not a place of peace."

Other options
Some of us feel that there is too much reliance on medication and too little participation from patients.

Ideally we would get more involved in getting better and would have access to literature, staff, libraries and so on to help seek out our own coping methods.

Socialisation
We missed the camaraderie of the old hospital and said that there were few opportunities and spaces for friends, visitors and fellow patients to mix and socialise in.

On some wards, it felt as though visitors were not really welcome and that staff could be a bit stand-offish.

Sections
The fear that we will be sectioned can ruin a stay. Being sectioned can make us feel very angry and apart.

Some of us feel that being sectioned is worse than the illness and makes a hospital stay unbearable. We feel that we are controlled and told what to do. When we are also restrained or forcibly injected then it is even more traumatic. Some of us worry that trying to overturn a section will make us unpopular.

Activity
Some of us feel that there are few activities that we want to join in with or are aware of. Many patients have talked about how bored they can get in hospital. Sometimes referrals for activities take too long – sometimes as long as a week. Some of us have ended up being discharged before our referral comes through. Occasionally we feel that the things we do are patronising and babyish.

Dependency
The very security and sanctuary that hospital provides can make us feel very safe. We can feel that we are protected and cocooned. This very support may prevent some of us from wanting or being ready to face the outside world. Some of us feel that hospital is a great disruption to

normal life that can remove our skills and confidence and ordinary life skills.

People don't want to be there
However good a hospital is, some of us just don't want to be there and wish to leave as soon as we can.

Admission
Some of us have not been able to be admitted when we felt this was very necessary. This can make us feel desperate and unsupported.

People who can't leave
There is a belief that there are some patients are only resident because there is nowhere for them to go to. This feels wrong.

Cleanliness
On rare occasions cleanliness has been a problem . On admission one person found a mess in the bathroom and sick on the walls of her room.

The courtyards
The courtyards in the hospital were meant to be pleasant and attractive spaces but are not. They should be improved.

The food
Whilst some of us like the food many others don't and think it is horrible.

Knowing what to expect
Some of us do not know what to expect, what the routine is and what we can and can't do or how long we are likely to be patients.

Mobiles and other phones
The ringing of mobiles can be very frustrating and the public phones don't feel very private.

Red tape
There is a feeling that some of the problems that we face with staff are due to the administrative and bureaucratic tasks they have to do which detracts from time spent with us.

Being in the wrong place

Some of us are in hospital but the real problem is a social one such as housing, benefits or harassment that the hospital can't help with directly. There need to be alternatives for these situations.

Alternative

Some of us are in hospital because community facilities that we would prefer are not available.

Pass

The pass system is appreciated but some of us have returned from being on pass to find our rooms occupied by someone else and our possessions stored in bin bags. This has been very unsettling.

Affric Ward

This is a huge improvement on the old locked ward at Craig Dunain and reports about its environment and staff are generally positive. However:

- It is unpleasant to be in a locked ward.
- Some people have been housed there in the past because of a lack of other beds elsewhere, which is wrong.
- It can be hard to relax or join in as we are locked in – as a result we can get very bored.
- Being a woman on the ward can feel unsafe especially if there are no other female patients.

Welcome

Arriving at the hospital can be a bewildering experience especially when confronted by the front entrance as it presently is. Ideally we would be met and welcomed at the entrance.

The nurses' station

Many people see the nurses' station as a 'goldfish bowl' which keeps people under surveillance as they approach. The fact that it does not look out onto the ward is also confusing.

DISCHARGE FROM HOSPITAL

This topic was raised a number of times. The HUG report on discharge is useful additional reading.

Community support

On discharge from hospital it is important that there is enough support to enable us to manage in the community. In addition it is important that we are told and given information on the community support and facilities that are available to us.

Halfway houses

For some of us a step between the community and hospital would be good. Aonach Mhor in Inverness is good for some but others would like to see more local facilities or local equivalents to the Braeside day hospital in Inverness.

Transitional discharge

This model piloted a few years ago is popular with HUG members who would like to see it become a part of discharge policy.

Motivation and skills

On returning home we may find it hard to get motivated and may find that we have lost many of our skills, confidence and abilities to cope at home. We will need help with this – especially in the early days. This process needs to start before we leave hospital.

We may be seeing the community mental health team or going to a drop in centre but we may be very alone and withdrawn. In this situation we need to be sure that we are not lost in the system and that people keep in contact with us but sensitively. Maybe access to someone that we trust who can visit regularly but unobtrusively.

Getting back into life

Equally on discharge we may need help to get back into life again; we don't necessarily have to become immersed in mental health services and the mental health world.

ACTIVITIES AND MOTIVATION

When staff became aware that we were holding these discussions they asked us to look at the activities people wanted in hospital and how to get people involved in them. They do provide a range of opportunities but were aware that many people lacked the motivation to take them up.

HOW DO WE GET MOTIVATED TO PARTICIPATE?

Is it a good idea to get involved in activities in the first place?

Yes – no matter how bad we feel, these can help us. However it can be very hard for us to agree to or get involve in any activity when unwell.

Often poor health results in lack of motivation and willingness to do anything which results in a downward spiral that makes us feel worse and worse.

Often our medication is very sedating and can completely stop us from doing things we would ordinarily have no problem in doing.

HOW CAN WE GET INVOLVED?

We need to be persuaded sensitively and gently by staff or our other carers. If left to our own devices we often won't get involved.

We need people to set up and organise activities, to encourage us and help us get involved. However we also need them to realise that sometimes we cannot participate and need to be left alone without feeling undue guilt or pressure because we couldn't join in.

We can often need some chivvying but it needs to be supportive chivvying. If we feel a part of what is happening then that helps too.

Sometimes the use of advance directives would help staff to understand whether we would like helped along or left alone.

If we have a good relationship with our key nurse it can help. Being in control also helps.

The key to getting involved is making sure that the things on offer are the things we want to do. We need people to find out what our interests are and to make what is being offered attractive. If we are uninterested or feel pressured and patronised then we won't join in.

Sometimes we feel as though there is little for us to do and that this is the reason we don't do anything. At others times we feel the activities on offer are designed to make us conform and therefore we can resist them. On occasion we just need to be left in peace.

However a strong message was, "keep trying to motivate us" (sensitively). We can feel that we are being badgered and dread each step of encouragement, but once we do join in we can end up feeling very good about it.

We did feel that many of the staff made a real effort to involve us. They make suggestions, offer to accompany us to places and yet resist the urge to push us too much. This is appreciated.

Ideally staff will walk gently along with us on the road to activity. Often doing something together can give us the impetus to get involved. The staff can be the catalysts to our involvement.

If there are things that are happening that we can sit on the edge of, that can be good. We may not be up to actual involvement but this form of diversion can help and set us on the path to joining in.

The best way to involve us is to discuss with us what we want to do and help us feel as though the whole process of being a patient needs to involve us and doesn't have to mean that we surrender control. The more we talk together as patients and professionals the more it will feel like we are in some form of partnership that we want to be involved in.

We also need to recognise our circumstances. We may only be able to do small and short things at any one time.

WHAT SORT OF ACTIVITIES WOULD WE LIKE TO DO?

The following is a list of suggestions from the branches:

- Access to research literature and coping methods.
- Access to the outside environment and city.
- Access to physical activity such as walking and gardening.
- Occupational therapy in all its forms.
- Swimming and sports such as volley ball and table tennis.

- The gym is good (but hard to afford out of hospital).
- Treatment and counselling
- Crafts, arts and games on the wards themselves.
- Make a purpose to activities such as crafts that can be displayed, sold and exhibited.
- Drama and other creative ways of expressing ourselves.
- Conversation and company.
- A chance to learn skills we can use on discharge.
- Music.
- Creative writing.
- Rudolph Steiner principles and activities.
- Role playing.
- Tai chi, Chi gong, relaxation and reflexology, massage and aromatherapy
- Access to computers.
- Art and art therapy and pottery.
- Nature walks and access to the wilds and the hills and the woods.
- Outward bound courses.
- Vegetable plots.
- Healthy eating and cooking.

We agreed that a number of these things are already happening regularly in the hospital. And that many of them have to be provided by qualified professionals.

We also felt that it would be good if many of these continued when we returned to the community and that it would be good to have more community occupational therapists to set them up.

CONCLUSION

In summary, this round of HUG meetings arrived at a number of conclusions:

The need for hospital services:

- Hospital services will remain necessary for many years and the need may increase.
- We find the idea that reducing acute beds may be justified in the near future unlikely.
- We do not believe there are adequate community services to reduce beds.
- We do not think that there is a clear correlation between increasing community services and the bed numbers that are required, however we do think that an increase in community services could eventually reduce the need for some beds.
- If it were proved that beds had become unnecessary and were lying empty we would accept the argument to close some beds.
- We do accept that there could be alternatives to hospital.

The value of hospital

For most of our members hospital provides a valued and important aspect of health care encompassing treatment, safety, asylum and sanctuary. Staff at hospital can provide great treatment and help people regain the skills and motivation to face the community again after illness.
The new hospital is much more pleasant than the old one.

However there are a number of negatives, which are included within the report. These include: sometimes poor attitudes from staff; difficulty in seeing staff when necessary; feeling bored and restricted from socialising with each other as well as sometimes feeling lonely in the single rooms.

Activities

The hospital already provides a range of activities and is good at motivating people to get involved we make suggestions for further activities and ways of involving us.

There are many points made in the text that we hope can be acted on. We hope the examination of these issues from the perspective of ourselves as patients adds to the debate about the balance between hospital and community services.

APPENDICES

APPENDIX 1

OTHER ISSUES ABOUT HOSPITAL

During our meetings a number of other issues were raised to do with hospital these are as follows:

- We need to know that our experience has been witnessed and vindicated.
- We need to be treated sympathetically as individuals with no labels about being good or bad.
- We need the degree of distress we experience to be acknowledged.
- We need to be given information that reflects our circumstances.
- We need to be treated flexibly.
- We need direct access to the hospital.
- We need an Accident and Emergency Department for mental health that anyone can go to.
- We need to be able to get help without a referral.
- We need treatment, respite for our partners and reassurance to ourselves and family that we will be safe.
- Sometimes our knowledge of what we need is ignored.
- We need access to laughter.
- We need support for friends and family.
- Sometimes GPs refer us because they don't want to take the risk of leaving us at home; communication between the psychiatrist and GP could help here.
- We need someone to sit with us to encourage us to like ourselves. Their care needs to come from the heart.
- Hospital should be a friendly environment with coffee, pamphlets and leaflets.
- We need a place to give comfort and security.
- Hospital should not turn into your home.
- We need more choice and more rights.
- We need encouragement to help us get on with our lives. We need to be able to live our lives and not be constrained by our condition or at least need to accept it and do as much as we can. We need to be all that we can be.
- Whether you go into hospital or not, should depend on the totality of how the person is.

- Admission should not depend on your GP or where you live.
- Advocacy is important.
- Access to the Citizens Advice Bureau is also important.
- In illness you can stop asking for help, you can feel a failure and people do not see the illness behind the face.
- We need professionals to react to our personality not just the illness they need to see our soul.
- Does the hospital fit the patients or the patients fit the hospital? We need to know that hospital has all the facilities to deal with any patients and any situations. How close are we to that ideal?
- It is not always necessary to resolve crisis in hospital. It can sometimes be better dealt with in the community. For instance by specialist intensive support at home.
- Empire building and hanging on to power should not be the reason people retain such places as hospitals or any other service. Don't allow culture to stop change; base change on what is needed.
- Therapy in hospital should allow you to break out of the place you are in and gain insight.
- It can be helpful to give up responsibility but then to move beyond that.
- Parents can worry about hospital; it can feel very threatening. They may feel that it will put their children at risk of being put into care.
- It's important that there is a partnership between staff and patients.

APPENDIX 2

POSITIVE EXPERIENCES

I was admitted to one of the wards in New Craigs for a short time and, although being in a position where you have to be in hospital can never be described as pleasant, I did find my time there as good as it could be.

At first I was very apprehensive and quite distressed. I was shown to my room and given a brief explanation of what the ward was like and what was likely to happen and then left to myself. This was good as I needed some space and time away from everyone and got it.

The next few days were a bit of a blur in my mind. I didn't sleep and didn't eat and couldn't relax or stop thinking. I didn't even stop moving. The staff gave me room to go through whatever it was I was going through. I particularly remember a time at four in the morning when I was feeling exhausted and one of the nurses offered to make me a cup of tea. It's sometimes the small gifts that make a huge difference. They were always there in the background respecting the choices I made whether that be to refuse sleeping pills or not eat and yet keeping me safe by not allowing the more damaging ideas I had to happen.

It is mainly the nurses that I remember, every shift one of them would come up to me to see if I needed to talk. They were all different, my primary nurse was quiet and supportive and practical; others radiated warmth and friendliness. There was one who made me question the strong beliefs that I had at the time. I remember lots of tears and a great deal of anger at him, but in retrospect I think his gentle ability to get me to question what I was thinking, led me to get better so much more quickly. I am glad the nurses approached me, as I would not have been able to ask to see them even if I really needed to talk. The chaplain was good; his support and the papers and books he lent me were much appreciated, as were the tissues to mop my eyes. I didn't really use occupational therapy though they came round the ward to see if we wanted to join in any activities. They did however let me use their computer in my room when no one else was using it; that was really, really good as I had so much that I needed to write down and say.

The doctors were helpful and respectful and gentle and even the one who sectioned me was courteous and clear in explaining why she did so.

And it is true the support we give each other as patients, I remember many journeys around the corridors and lots of little gifts and gestures of support. Then there were the visitors – I was lucky in that lots of people came to see me, it was good to retreat to my room to speak with my family and friends. In fact my room became my sanctuary – somewhere to hide away when people were too much, somewhere safe and secluded and mine, my own space to escape to or to muse or just get some privacy.

I had a great deal of anger about the drugs I was asked to take, and still do to an extent, although intellectually I agree with the decision that was made. The pharmacist among others was very helpful both in giving information and explanations but also in appreciating why I was so against the medication.

What didn't I like? I suppose, especially once I was well, was the boredom. You could see people in the gym or going off to art therapy or O.T. but you didn't really know how to get into it. But it's more complicated than that; I didn't really feel up to doing anything. I was either being weird (as my son would call it) or sleeping and hiding and although I didn't want to do anything, I also had a feeling of what on earth is there to do? The telly's boring, the corridors uneventful, I couldn't concentrate to read and didn't always feel up to talking, but I felt completely lost for any form of occupation or ways to distract myself.

The bit that really worried me was that there was a rumour that one of our fellow patients had abused people, and if the rumour was wrong, then it should have been stopped, and if it was true then I have a great deal of sympathy for some of the women who found him hard to put up with.

The best bit was having the room to be whoever I was being at this confusing time in my life and having this space and place where I was given a balance of freedom and safety. The very best bit was getting home quickly once it became clear that I was well. A last touch was having my get well cards forwarded to me after I had left, I never expected them to do that and it meant a great deal.

APPENDIX 3

POSITIVE EXPERIENCES

GOOD POINTS

- Hospital gives time out from problems, and time to find yourself again.
- Having your own room is so good; a place to give you sanctuary and a private bathroom is great.
- Access to Occupational Therapy was great, and it did not take long (2 days) for this to be set up. It gave me space to find I could achieve things again.
- No smoking was good. It was also good to have specific smoking areas as I realised that this was important to some people. The old hospital was quite unpleasant, having smoking in all the shared areas.
- It was great to be segregated from men, compared to the old hospital where I was on a mixed ward, chatted up by two men, and phoned up by one of them for 4 weeks after his discharge. It was great to switch off from these stresses in a single sex ward.
- The Social Centre was good, particularly with the ability to see other patients, do activities and have an excellent choice of videos. It would have been good if this could have been open for longer periods and have a few other activities, for example crafts/drawing and computer/internet access.
- It was great making friends of other patients and understanding that you are not alone with your problems. There seemed a great comradeship on the ward.
- The relaxed attitude to self-harming was good. You were not made to feel 'naughty', and being given a greater understanding of self-harm was good.

PROBLEMS

- You do not know the staff. I even had a different psychiatrist, and did not feel comfortable with the change from my community mental health team.
- It was often more difficult to access staff than in the community. They were always busy with someone else. I saw the psychiatrist less to talk to one-to-one than I did in the community.
- The cleanliness was poor. I did not shower the whole time I was in hospital because of the vomit in the shower when I was first admitted. Although this was cleaner after I asked, I preferred to use

the bath facilities. Some of the staff there for cleaning were very grumpy and all too ready to off-load their problems.

- It was difficult to watch the channel you wanted on TV. The same soaps would be on in the lounge, smoking room and social centre. Maybe access to a portable TV would be nice.

APPENDIX 4

COMMENTS RECEIVED AFTER THE FIRST RELEASE OF THIS REPORT

I read your report with great interest. It is evident that HUG continues to play a very important role in helping NHS Highland improve mental health services. As ever, the personal insights of users are extremely valuable.

Kevin Woods, Chief Executive NHS Scotland.

… As with all their reports it is a very stimulating read and the service users involved are to be complimented on the refreshing degree of honesty which pervades this report.

I always wonder if a similar and anonymised report was compiled from the views of service professionals how much overlap we would find with the views of service users and would such a report help to break down some of the barriers to good care described so succinctly by HUG."

Peter Connelly, Associate Medical Director for Public Health, Murray Royal Hospital Perthshire.

" Many thanks for this which is very helpful… I found this document crystal clear and very informative….. I am very happy to be of any help I can be here in the Parliament and would be happy to forward your paper to all the MSPs in our group, who may want to look at it s recommendations which I think apply to most, if not all of Scotland."

Fergus Ewing MSP

"I welcome the latest in a series of excellent reports by Highland Users Group. The views of 73 members were taken to produce this considered and balanced report …… I will now be asking the Health Minister, the Mental Welfare Commission and NHS Highland what action they are taking in response to the many issues raised in this report.

Mary Scanlon MSP

"I have read it through and found it absolutely excellent. It provides a detailed, balanced commentary on so many aspects of hospital care. I could not think of anything that had not been covered. I have identified no factual errors and am very supportive of the document. I hope that it gives rise to much fruitful and productive discussion."

Dr Chris Macgregor, Clinical Lead for Mental Health Services, NHS Highland

"I think this report should be widely circulated for use throughout the service and am happy to support this."

Jackie Agnew, Service manager, Mental Health and Learning Disabilities, NHS Highland

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)

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