



Highland Users Group

RESPIRE CARE

**The views of Highland Users Group on Respite Care (or
Short Breaks) for People with a Mental Illness**

April 2002

Highland Users Group can be contacted through Graham Morgan, Highland Community
Care Forum, Highland House, 20 Longman Road, Inverness IV1 1RY
Tel: 01463 718817 Fax: 01463 718818
e-mail: hug@hccf.org.uk

Highland Users Group

The Highland Users Group (HUG) was established on 11 June 1996.

Its aims are to:

1. Represent the interests of users of mental health services living in the Highlands.
2. To identify gaps in services and to find ways of improving services for mental health service users.
3. To provide information about mental health issues to users living in the Highlands.
4. To participate in the planning and management of services for mental health service users.
5. To pass on information and news amongst mental health user groups in the Highlands and to interested parties.
6. To increase knowledge about resources, alternative treatments and rights for users of mental health services.
7. To promote co-operation between agencies concerned with mental health.
8. To promote equality of opportunity and to break down discrimination against people with a mental health problem.

At present (April 2002) HUG has 251 members and 13 branches in:

- ◆ Caithness
- ◆ Sutherland
- ◆ Easter Ross
- ◆ Wester Ross
- ◆ Nairn
- ◆ Inverness
- ◆ New Craigs Hospital
- ◆ Lochaber
- ◆ Skye and Lochalsh

Between them, HUG members have experience of nearly all the mental health services in the Highlands including Child and Adolescent Services and Services for Older People. However, our reports mainly reflect the views of 'adults' with experience of mental illness.

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Introduction

Respite care has traditionally been seen as a mechanism for giving carers a break from looking after users, either by sending users to facilities that can cater for their needs and providing carers with some time to themselves, or by bringing in people to look after users in their own homes and giving the carers the opportunity to get out for a while.

However, in HUG, there is a feeling that many users also have their own needs for respite care.

The subject of respite care has been discussed in the network of HUG branches on two occasions; once in the early days of HUG in 1997 and more recently in November and December 2001. On both occasions the discussions took the form of a series of informal questions and conversations with groups of members.

On the first occasion we involved approximately 45 members and on the second 63 members participated. We have only used the results of the second set of discussions and some material sent to us by HUG members as the basis for this report. This was because we wanted to make sure that any report was as up-to-date as possible.

This report is a reflection of the views of users of mental health services rather than that of carers. Therefore this report has a value in being a reflection of a relatively unknown perspective on many of the issues that carers have talked about in the past.

When we first discussed the subject in 1997 most members of HUG had not heard of respite as a service and very few had had access to it. However people had frequently talked of the need to find relief and refuge from the pressures of their illnesses and home circumstances and the idea of respite had great appeal.

Over the intervening years more and more people have experienced respite, especially at Catalina House Nursing Home. Many people had become aware that respite care now existed as a service for some people.

When looking at the principles and ideas behind respite there was a lot of agreement between the ideas expressed in 1997 and those of today.

The idea of being able to get a break, to escape for a while, to have somewhere to pause and reflect in relative safety were still seen as very important.

Being able to look forward to a planned break in the future gave hope to many people and to be able to seek refuge when approaching crisis was seen as potentially life saving by others.

The fact that people now had to pay some of the costs of respite care caused concern among HUG members, especially as respite used to be provided in hospital as a free service and was now mainly available via Social Work funding through a privately run facility.

Although members could see that some forms of respite are mainly there to help carers it became clear that this could be just as much a service to users and that these distinctions sometimes blurred the issue: users can be carers and vice versa. Both can be parents or partners and all can be in need of a break either from each other or from the situation that they are in.

Over the course of the meetings it became clear that respite care should be a service that was available to anyone with a mental illness and that it should become a routine possibility when helping users plan their care.

It was seen as a service that could play a large part in preventing illness and in promoting health and, as such, could play a positive and cost effective part in helping people remain in, and build on, their lives in the community.

Is Respite Care Needed And When?

Most HUG members agreed that respite care was very important and that, in its different forms, it should be a key component in the options for a person's care.

There were a number of situations where it was needed:

- 1. To recover from trauma. For instance, as a way of getting back on your feet after an acute episode of illness or even after hospital admission.**
- 2. To stop a crisis that is building up from developing any further:**

"In the early stages – when you are getting symptoms as early warning signs."

"We need respite when we know that we need it. Social Work came on Tuesday and I was in respite care by Wednesday – it was brilliant."

3. As a way of maintaining and enhancing your ability to manage at home and in the community:

"Respite can be the difference between coping with illness or relapsing - a relapse can put you right back where you started, while respite recharges you and helps you face life. Ultimately it saves money"

"When you get sick of being alone, you just need to escape - life has become like a prison and your house has become like a prison."

"People usually get such things in crisis but if you could plan for and ask for it in time it could keep you going."

4. It is needed as an experience in itself; a change of scenery and people improves the quality of people's life:

"Just a break from each other, when you can get away for quiet time to think and reflect on the situation."

"There is a need for a place to rest and also for a place with the structure and the ability to motivate you."

5. It is needed to give those around you a break so that they too can cope better.

"If you are caring for someone you can get to your wits end and need a break and out of the situation"

"People can be trying to manage to look after their physical and mental health, but end up in hospital because their carer can't cope."

"When the whole family situation is becoming unmanageable, it is often not one person who is mentally ill in the family it is many."

6. It is needed when you are not acutely ill but can no longer manage:

"When you can't get out of bed or attend an appointment."

"When you are so unwell that you are mentally exhausted, when you can't cope anymore, when you get physical symptoms of stress, when your body is exhausted and when your mind is telling you to give up."

7. As an option for people in distress but not “ill”.

“When you are in a crisis but don’t have the good fortune to meet the clinical criteria so that hospital is not an option.”

8. It is needed as a tool for change:

“ It can also be needed when you need a permanent change and need to reflect in your own space, in order to make a decision that you will be happy with.”

“...This could be helped even more if there was a period of follow up once you left respite care.”

9. To help you with your own responsibilities (such as childcare):

“If you are a single parent and under stress the only break you get is when your children are at school. However if your kids are under five you can get really stressed.”

“Even getting out for an evening can be really good. If you are not getting out you can end up staring at the four walls, but somebody coming in to baby sit can be great, otherwise you feel imprisoned”

It was also said that respite care should be something that people want to receive, not something they have to take.

KEY POINTS:

- **Respite care is an important part of a person’s treatment.**
- **It can both provide a break and recuperation, room for enjoyment and room to look at a person’s situation in safety.**

Where Should Respite Care Be Provided?

There were a variety of opinions about this, but the main theme that came out was that respite should represent a complete change of environment away from the stresses that people are experiencing.

"The whole point is to get away from everyone including your carers; otherwise there is no difference."

Most people would want to be away from home and their community and in many cases their family.

There was a feeling that a few people might like to be fairly near to home but that this was not the case for the majority.

"Some people would like local respite but then you can end up feeling on top of each other. People can feel obliged to visit and then the problem is still there."

Most people suggested that they would like to be in a peaceful, relaxing, quiet place away from any hustle and bustle.

There were some (and the impression was that these were mainly younger people) who yearned to go somewhere lively and exhilarating and yet still safe. Perhaps a purpose built facility in one of the central belt cities.

"Other people want a more active break. They want to be able to go off and do things, almost having a package of things and yet not feeling looked after."

There was a suggestion that some people will be in respite to learn how to manage their lives better and that in these situations it would be good to have links with the community that they come from.

KEY POINTS:

- **Most people would like a break to occur away from their usual environment. However there needs to be some choice in the place a break occurs.**
- **Many people would like a break to occur in a peaceful setting although there are some that would benefit from a more dynamic environment.**

In What Sort Of Place Would People Like To Get Respite Care ?

Again the emphasis for most people was a relaxing, attractive and peaceful homely place:

People suggested:

- A converted farmhouse.
- A small guesthouse with a sympathetic landlady (or a hotel.)
- A nursing home.
- Existing facilities such as Catalina House or the hospital.
- A residential caravan that could be booked as and when needed by people who use community facilities.
- It could be a dedicated facility – perhaps tied into other resources such as ‘places of safety’ or drop in centres.

“It should be quiet and away from the public gaze.”

What Should People Get Out Of A Respite Care Facility?

There were two main themes to this:

1. Respite, for some people, should be purely a place of relaxation and recuperation, something that they can look forward to and enjoy.
2. Respite for other people should be seen as an opportunity to take time out, with support, to look at their lives and home environment and develop the capacity, skills or confidence to cope with it better on their return.

“Something like a rehab programme without the breakdown.”

The point was made that many people with mental illness end up on “maintenance” doses of medication as part of their treatment. People were keen that therapies such as respite care should also be seen as “maintenance” treatments and as a valued part of a person's care.

For a list of the main things people wanted to get out of a respite care facility see Appendix 2.

KEY POINTS

- **Respite care involves four main elements;**
 - Refuge and relaxation.**
 - Something to look forward to.**
 - Having things to do and enjoy.**
 - Having time to reflect and learn.**

What Should Happen In Respite Care?

Again the main emphasis was on peace and tranquillity. Many people wanted to do very little except to relax and unwind and be looked after. However, a significant number of people were looking for therapy or activity where they could both examine their lives and explore new ways of coping or find enjoyable activities to do or ways of recharging.

A point was made that a respite care facility could be similar to a hospital except that there were less medical criteria for admission and that it is used before things get too bad.

And on a similar theme:

"It should be different to a hospital. It should be jollier, there should be more chances to join in, there should be more leisure activities and it should be more like one of the drop in centres.

It should be a place to go to do things when you are still happy enough to do them."

For a list of the main things people wanted to happen in respite care see Appendix 3.

KEY POINT

- **Respite care can help people get back on track through experiencing positive activities in a setting in which they are relaxed and open to change.**

Other Forms Of Respite Care

The previous descriptions have mainly referred to respite care provided with staff in a place designed for that purpose. However, although the principles of what people were wanting remain the same, there were other different ideas suggested that would give people a break.

These were:

Holidays:

Many people were very clear that a break in a nursing home or hospital provided much less enjoyment, much more stress and much less benefit than if they were able to spend some time as a family on holiday.

It would be, and is, hugely therapeutic for some people and far less costly than the inevitable hospital admissions that people endure when they do not have access to any form of break.

"Lots of people need a break. Getting a break in a 'normal' place could be as good or better than a specialist facility. If you had to go to a specialist facility for respite care you could be nervous that you weren't getting a real break."

"If you are able to work then you can get a holiday, but if you are on benefits then you are living from day to day and a holiday is not possible."

"To get away, a chance to be whole and to stabilise is very cost effective ultimately. They should subsidise these things because the majority of us can't afford holidays. Not everyone wants to go to a nursing home. People often want to get away and do something that they really enjoy"

"Where should respite occur? The South of France! Wherever suits you – it depends on your likes, dislikes and hobbies."

KEY POINT

- **Respite care does not always have to be a specialised service. A holiday can fulfil this function for some people.**

Supported Holidays

Many people are not well enough to take holidays. However groups of users have visited other drop in centres or been on trips and holidays.

" A holiday can be hard to cope with. If we had a group of people who could support each other and maybe some staff too, then people could get away for a break. Just to be able to achieve this would provide a break and increase confidence in itself."

"People need to get away from their usual environment. Simple things like visits between drop in centres. Respite should be something to look forward to - it should be something different. It should be a chance to meet people in similar situations."

KEY POINT

- **Many people can benefit from a break - some people need support to do so.**

Daily Respite

Many people said that the facilities that they use in the daytime give them a break and provide support as well as giving reassurance to carers:

"Places like the Training & Guidance Unit (TAG) where you can offer each other support, even if only in the short term, are very useful. They help with daily respite care."

"Coming to places like the Gardeners Cottage gives our carers and relatives a break and it also gives us a break."

"Being with other people with a mental illness is very good. It helps in itself and is healing in itself – being with each other and sharing problems and experiences."

"People 'on the outside' can't always see how being together can help and can try to stop us mixing as it seems so negative to them."

KEY POINT

- **Respite can be provided through people's use of other facilities.**

A Cheap Facility To Stay In

There was a feeling that different organisations or groups of users could share the cost of cheap places to stay, like a guesthouse or a caravan, to give breaks to those that can manage such things but without the cost of a major holiday.

Short Term Respite

Some people, especially those with other disabilities or with dependants and who may also be either users or carers or both talked about the need to have short breaks at home. The chance to get out in an evening to meet friends or have a drink were incalculable to some people. If this was combined with practical help in the home the benefits were huge.

"Respite is not just a break. Things like getting home care when you can't manage is just as important ... the combination of practical assistance and a chance to recharge is just as important"

"The more services like 'Crossroads' are recognised, the less stigma there will be about getting respite. We need people to become aware of the need for respite."

Equally there can be problems with getting people in to help:

"Getting totally away can be the solution but it can be impossible to afford. Even baby sitting can be difficult to afford or arrange – you need someone who knows your child and what they are like."

"What if you get a carer in to help and you don't like the carer?"

And if respite is withdrawn:

"You can hit rock bottom – it can be so dangerous – you are living close to the edge and then the respite goes. Withdrawing it can send you doolally."

There was a feeling that this sort of short break (mainly for carers) was especially important where a person was very ill and needing constant care and support.

"If you are looking after someone 24-hours a day then it would be great to go out in the evening and know there is support."

"One form of respite for carers when we are ill would be 'person sitters', a form of companionship for users that would allow carers a break, similar to the help Crossroads gives."

It was also something that would apply to parents with a mental illness who were struggling to look after their children.

KEY POINT

- **Some people, especially carers,(who may also be users) can and do benefit from short breaks provided at home.**

Alternatives To Respite Care

There was also a feeling that the need for respite would be reduced greatly if we had the confidence to make friends and to go out into mainstream life ourselves.

Courses that would:

- build confidence,
- help with everyday situations,

- help with life skills,
- help us face difficulties in life in safety,
- help us to regain the ability to have fun,

would all reduce the need for respite care and enhance our ability to engage with life.

KEY POINTS

- **Respite is not the only way in which people can regain the confidence to live a quality life in the community.**
- **It has to be seen in conjunction with a range of community support options.**

How Is Respite Care Different To A Holiday?

Many people thought that holidays could be as therapeutic as conventional respite care and that people should be supported to go on them:

"[Holidays and respite] are exactly the same thing."

"If it were possible, a proper holiday would be ideal for some people."

However, we also felt that it was important to make a distinction between the respite that a person may get as a service and a conventional holiday.

The main distinction was to do with illness:

"You would generally get respite when you are unwell. You don't go on holiday when you are unwell"

"If I went on holiday I couldn't manage because of the likelihood of things going wrong"

It is also a service where people receive support and back-up of a kind that they wouldn't get on holiday.

"Respite is much more about support and space and safety. In the situation where you need respite you couldn't manage a holiday – you need something specialised with psychiatric support."

"A holiday can be very stressful. Respite would be a break or holiday without the pressure."

KEY POINT

- **For some people respite care and a holiday are the same. However, for other people there is little similarity - respite is a form of treatment and support.**

Respite Care and Hospital

What Is The Difference Between Respite Care And A Hospital Admission?

In some circumstances the difference between an admission to hospital and getting respite care can be blurred. This is especially so when people feel that they are in crisis.

There was a call for clear differentiation between the two options. A small number of users had ended up in respite care when they had thought they were being assessed for admission to hospital and had felt very confused and angry when they realised that they had to contribute to the cost of their stay.

Generally people thought that respite was a facility to be used when people were a little better. It was something which people could build on and use to keep going.

The difference was partly symbolic:

"Respite is for when people are going up - it prevents hospitalisation or getting worse."

"Hospital care for many is not an option - it can make you much worse. Hospital can make you fit into the role of illness and then escalate the problem."

"Where you get help can dictate or influence how you react or respond."

"It is important to get away. Hospital is not always appropriate - it can make you tense up."

KEY POINTS

- **There needs to be clarity about when a person will be admitted to hospital and when it is more appropriate to admit them to a respite facility.**
- **Respite is more about promoting health than dealing with illness.**

Respite Care In The Past

Until a few years before the closure of Craig Dunain a number of people received regular respite breaks there. However this no longer appears to happen in the new hospital, New Craigs.

In the recent meetings of HUG the effect of this was spoken about.

Although nowadays the majority of people would not want respite in hospital as a first choice, the people who did get it there in the past greatly appreciated it.

The patients who received respite in hospital were mainly people who had been ill for a number of years. They found it very hard to cope in the community. The respite with a degree of support and back-up kept them going – it helped them feel refreshed and able to cope:

"It was a good place, you were not put under pressure, the staff were excellent - there was freedom there, it gave a rest and was like a mini holiday. There was enough care and enough support, you didn't have to do anything at all, you knew everyone and it was familiar and safe."

People felt that the effect of withdrawing the respite in hospital was that this particular group of people got into crisis much more frequently nowadays. They were admitted to hospital as emergencies more frequently and remained ill and distressed for longer.

"It used to be a part of your treatment. It was a load taken off you. People staying in the community couldn't always manage, but this maintained people's health by being planned at regular intervals."

Should Respite Care Ever Be Provided In Hospital?

Some people thought that hospitalisation should be an option for people needing respite care, especially where it is being used as a response to a person who is clearly becoming more and more ill.

"It depends on how bad you're feeling and how desperate you are. Hospital is an option when you are very close to being admitted anyway."

For some people hospital was a place of safety and familiarity and remains such a place. For them, respite in hospital would be the preferred choice.

However, for the majority of people hospital can be a busy and traumatic place where the calm and peace that respite should give will not be achieved.

"We need a place for quietness, which you don't get in hospital or at home."

"You can just want to get out of the situation, to hold onto something that you enjoy. This is not helped by being shut up in New Craigs"

"It would be scary to get respite (in hospital)"

"Even going into hospital can be a break. Away from knowing friends and family. Alone and away from everyone that knows you – away from their expectations."

KEY POINT;

- Respite care is sometimes best provided in a hospital setting but should generally be provided away from hospital.

Should Respite Care Be Provided Only In A Mental Health Setting Or With Other Client Groups?

Most people felt that although we could learn from people with different disabilities, when we are getting respite it should be amongst our own "community", people whom we know will understand what we are going through.

KEY POINT

- Respite care should be provided in facilities dedicated to the needs of people with a mental illness.

Would Respite Care Help Prevent Hospital Admission And Help People Cope In The Community?

Although this would not be its only objective most people felt that properly planned respite care could stop later admissions to hospital. As part of a range of community packages it should help people manage their lives better in the community. However people were also keen to say that:

"Respite care is a good idea if only because it reduces human unhappiness."

Key point

- **Respite care may be able to reduce hospital admissions and enhance a person's ability to cope in the community.**

Should People Pay For Respite Care?

In the past many people received respite care in hospital without charge. The fact that people have to contribute to the cost of respite care has caused a great deal of anger.

However, there were two main themes to people's discussions on this subject:

Many people said that paying for respite care or contributing towards its cost was wrong.

- This was because they and their partners or carers couldn't afford it. Many of their costs at home continued when they were receiving respite care. The worry about money and the lack of money for any form of "treat" when in respite care all made it less of a positive experience than it could have been.

"Having to pay a lot of money for respite care misses the point of it. If you have to pay for respite as well as cope with the costs that continue at home, then the relaxation and peace that you can get disappears. You can spend more time worrying about your bills and more time worrying about costs within the centre."

"For some people on low benefits it would be impossible for them to afford respite care, only those that are relatively better off can afford it."

- The other reason was because people saw it as an essential part of their treatment plan. They felt that in a country with a welfare benefits system and a free health service, the practice of contributing to the cost of respite care (which most people thought was principally a service to maintain health) could not be justified.

"A psychiatrist said that I needed respite. If instead he had said that I needed hospital then I would have got it for nothing."

"You need to know you will have money. If respite is to work you need money. People should be able to get tobacco and the occasional pint."

- There were, however, many people who thought that a token contribution that did not cause hardship was justified. It symbolised a commitment to the process and encouraged people to get the maximum benefit that they could out of their stay.

"People don't mind contributing but they shouldn't suffer because of this."

- Some people thought that if people were getting respite care, and that they had an income above the income of people on benefits, then a charge would be justified.

When we were discussing holidays as a form of respite most people could see the point of contributing to this (although they pointed out the need for some financial assistance as many people did not have the resources to pay for a break entirely out of their benefits.)

People do need to know in advance if they will have to contribute to the cost of respite care and care needs to be taken to ensure that the person is in a fit state of mind to take in this information.

A point was made that people were only entitled to subsidised respite care for four weeks in the year. This caused considerable anxiety for some people who felt that this did not reflect the intensity of the need that they had for breaks from their home environment:

"You are only allowed 4 weeks respite care a year. You can end up trapped. It can get really bad, you don't know what to do, you can fret over it and feel worse."

KEY POINTS

- **If people do have to contribute to the cost of respite care then that contribution should only be a token one.**
- **Respite care is a form of health (and perhaps social care) whose cost should mainly, or entirely, be born by the state.**
- **There should not be a time limit for respite care - the time spent in respite care should be determined by an individual's need.**

Transport

Members felt that if people had to travel in order to get respite care then there is a need for their travel expenses to be paid or subsidised.

Other people who struggle with travel may also need assistance with the travelling itself.

There may also be a need to pay the costs of carers who have to travel to visit people.

KEY POINTS

- Peoples travel costs to and from respite care should be paid for.
- People who have difficulty in travelling should be given assistance if necessary.

Parents And Respite Care

This was a hard subject to find solutions to. It was agreed that parents with mental health problems are often particularly in need of respite.

They need breaks away from their children (perhaps relations could look after their children or workers could come in to look after the children), but they also have a need to go to a facility that caters for families together. For instance, a set of cottages with support.

However, it is important that children do not feel that they are the reason a parent needs a break or that parents feel that their children are seen as at risk if the parent admits to the need for a break.

Generally there was a need for facilities to become parent and child friendly, for instance, through the provision of crèches.

KEY POINTS

- Respite care can be particularly important for parents. They need room both away from their children and also together as a family in family friendly facilities.

Accessing Respite Care

Not everyone knew that there was such a thing as respite care and other people felt that they were not given it as an option.

Some people also felt that they would have to be very assertive to gain respite care.

There was a call for more publicity about respite care:

"It can be very difficult for, say a couple, to get a break. There can be a lot of guilt. It could be very hard to ask for it. You may need someone to suggest it."

"... If they could experience how respite works then people would know enough to ask for it and seeing the good it could do could make it easier."

KEY POINTS

- **There should be more publicity about the availability of respite care.**
- **Users sometimes need to be helped to ask for respite care.**

What Is Respite Care Like Now?

Most people who had experienced respite care had done so at Catalina House Nursing home.

There was a range of opinion about this facility:

Some people thought that it provided a great break. It prevented hospital admission and made life survivable:

"We see nothing wrong with the unit, the staff are good and so is the Manager. They have given me a chance and done me proud – I'm getting something out of it."

"It's nice to know that there are skilled people only a few seconds away who can give you help when you need it. If you were trapped at home you could end up sitting really scared and eating all your medication"

"It was quite useful. I needed some space which I got. It was useful that it was isolated and away from town and people. Looking back I probably benefited - I needed away from the scene - I didn't need institutionalised."

However there were a number of people who were extremely critical of the place. Some because of their feelings about a few members of staff, but mainly because of its isolation and distance from facilities (it is situated on an industrial estate outside Alness), and because of the fact that people using the facility often had little money available to them.

There was also criticism that there was very little to do at the centre:

"Being able to go there and having support and peace is very good and therapeutic for some people, but other people who have gone have felt the lack of things to do made it very boring."

There was also worry about the fact that the facility is a private one:

"It is a tragedy that a place that is meant for respite has been established to make a profit."

A more general point was made about people's prospects when their stay ended:

"Respite is very useful but it doesn't change what you are going back to. No matter how well I am treated here, the reality is that I have to return home. I can get very anxious, especially when the time to leave approaches, knowing that I have to go back home eventually."

Some of the longer term residents of Catalina House and other residential facilities made the point that, although they lived in a place that also provided respite, they also needed respite from the centre itself. This illustrated the point that the essence of respite care is to provide a break from the situation you are in and the people you are mixing with:

"People still need a break from Catalina. There is nowhere to go if you live there. You need a choice in where you are going. Everyone needs a break"

"It (respite care) would be a good thing even if people were already in hospital or residential accommodation."

KEY POINTS

- **There is a need for choice in the respite care on offer.**
- **Some people object to receiving respite in private facilities.**

- Respite is needed for people already living in residential settings.
- There are varied opinions about current provision of respite care.

Respite Care And Peoples Carers

Traditionally respite care is a term used to describe services, which give carers a break from the people they are looking after.

We discussed the respite care aimed at assisting carers in the HUG branches:

Do Carers Need A Break And Why?

Everyone agreed that just as we need a break from carers, they also need a break from us. In some circumstances it was felt that it was absolutely essential for carers to have a break. The reasons people had for this were:

"Everyone needs a break. You can get fed up with the sight of each other whatever your situation."

The stress of the situation:

"They can end up tearing their hair out in frustration and get ill themselves."

"If there was no respite then we would worry about our carers and start to feel very guilty."

(At the time of the meetings we were aware of one carer who had been admitted to hospital as a result of the stress of caring for another person.)

"They need it because they are on duty 24 hours a day. If the client is getting into problems then they can nip it in the bud before the carer gets snowed under or it develops into an acute illness."

"Carers can themselves end up feeling that they will end up in hospital. The sleepless nights can be very draining. You have to have a break if you are to continue looking after someone."

"They need a break away from worry, they need a bit of peace. It's hard to know they need a break - but its reality."

Some people also made the point that neither users nor services providers should ever take it as inevitable that carers will provide care, and also that if carers are looking after us they should be guaranteed access to respite if they need it.

General Points About The Help Carers Need

A number of other points were also made about carers when they are caring for people:

"Carers can come under a lot of pressure when they see their relative is really ill and they try to help but cannot do anything."

"It can be very frustrating when they are trying to help but cannot find answers or even information. This can be made even worse by rules of confidentiality. There is a need for advance directives and for carers to meet with each other and to share concerns and support."

"Apart from a break Carers need:

- *Some form of help in knowing what to do and how to care.*
- *Getting basic information and skills can be really good.*
- *Knowing what to expect*
- *Often there can be a big strain but carers don't know who or where to ask for help.*
- *They need recognition for the job they do."*

It is clear from this that both carers and users can desperately need a break. However the form of this break can vary. It seems that although users and carers often need a complete break away from their environment and situation, carers also have a need for short breaks away from the user at times when the user needs a lot of assistance.

"If you are ill then your carers will need a break. You need looked after in your house usually."

KEY POINTS

- **Carers can have a great need for respite from the situation that they are in.**
- **The respite they need may not always correspond to users' needs for respite care.**

How Do We Feel About Carers Needing A Break?

Amongst some communities there is sometimes a feeling of resentment that people could believe that our friends and relatives could need a break from the reality of our lives.

It is sometimes seen as demeaning that users should need to be 'looked after' in order that their loved ones can recuperate from their presence.

We looked at this within the HUG groups and found that, although some people did have feelings of guilt about the fact that their partners and friends needed breaks, for the majority of people it was just a part of their lives.

It was very easy to see why everyone, when faced with the reality of mental illness, may need a break from it:

"It is a natural part of our situation. We know they need a break"

"We are well aware that we can be a nuisance at times. We know that they need a break."

"Knowing that people need a break from us is something that you have to resolve in yourself, but it is still something that has to be done."

"We need realism and we must realise that those closest to us need to take a step back to clear their own minds and chill out."

"It's a fact of life."

KEY POINT:

- **Although some people can feel guilty about the fact that their carers need a break, most believe that it is a part of life to which people need to adapt and accept.**

Conclusion

Users and carers and their dependants often have limited access to breaks that will reduce the impact of mental illness on them and their families.

Breaks can take the form of conventional respite care in specialist facilities or breaks within the home or they can consist of breaks away from home in the form of holidays.

Respite care is not only a way of recuperating; it can be a chance to look at a person's situation, to review it and make decisions and learn skills that will help people manage better in the community.

Members of HUG believe that access to respite care should become a routine option in a person's treatment.

Any payment for respite care should (at the most) consist of a token contribution (especially for those on a low income). Users should not lose out because of the worry they have about their finances.

This report has been ratified by the HUG Round Table and will be sent out to key professionals within and outside Highland. It is available from the HCCF office at Highland House, 20 Longman Road, Inverness IV1 1RY (Telephone 01463 718817).

The report will be presented and discussed at future HUG 'Round Table' meetings involving people planning services in the Highlands.

Key Points

Is Respite Care Needed And When?

- Respite care is an important part of a person's treatment.
- It can both provide a break and recuperation, room for enjoyment and room to look at a person's situation in safety.

Where Should Respite Care Be Provided?

- Most people would like a break to be away from their usual environment. However there needs to be some choice as to where a break occurs.
- Many people would like a break to be in a peaceful setting although there are some that would benefit from a more dynamic environment.

What Should People Get Out Of A Respite Care Facility?

- Respite care involves four main elements:
 - Refuge and relaxation.
 - Something to look forward to.
 - Having things to do and enjoy.
 - Having time to reflect and learn.

What Should Happen In Respite Care?

- Respite care can help people get back on track through experiencing positive activities in a setting in which they are relaxed and open to change.

Other Forms Of Respite Care

Holidays

- Respite care does not always have to be a specialised service. A holiday can fulfil this function for some people.

Supported Holidays

- Many people can benefit from a break – some people need support to do so.

Daily Respite

- Respite can be provided through people's use of other facilities.

Short term Respite

- Some people, especially carers (who may also be users), can and do benefit from short breaks provided at home.

Alternatives To Respite Care

- Respite is not the only way in which people can regain the confidence to live a quality life in the community.
- It has to be seen in conjunction with a range of community support options.

How Is Respite Care Different To A Holiday?

- For some people respite care and a holiday are the same. However, for many people there is little similarity – it is a form of treatment and support.

Respite Care And Hospital

What Is The Difference Between Respite Care And A Hospital Admission?

- There needs to be clarity about when a person will be admitted to hospital and when it is more appropriate to admit them to a respite facility.
- Respite is more about promoting health than dealing with illness.

Should Respite Care Ever Be Provided In Hospital?

- Respite care is sometimes best provided in a hospital setting but should generally be provided away from hospital.

Should Respite Care Be Provided Only In A Mental Health Setting Or With Other Client Groups?

- Respite care should be provided in facilities dedicated to the needs of people with a mental illness.

Would Respite Care Help Prevent Hospital Admission And Help People Cope In The Community?

- Respite care may be able to reduce hospital admissions and enhance a person's ability to cope in the community.

Should People Pay For Respite Care?

- If people do have to contribute to the cost of respite care then that contribution should only be a token one.
- Respite care is a form of health (and perhaps social care) whose cost should mainly or entirely be born by the state.
- There should not be a time limit for respite care – the time spent in respite care should be determined by an individual's need.

Transport

- Peoples travel costs to and from respite care should be paid for.
- People who have difficulty in travelling should be given assistance if necessary.

Parents And Respite Care

- Respite care can be particularly important for parents. They need both room away from their children and also time together as a family in family friendly facilities.

Accessing Respite Care

- There should be more publicity about the availability of respite care.
- Users sometimes need to be helped to ask for respite care.

What Is Respite Care Like Now

- There is a need for choice in the respite care on offer.
- Some people object to receiving respite in private facilities.
- Respite is needed for people already living in residential settings.
- There are varied opinions about current provision of respite care.

Respite Care And Peoples Carers

Do Carers Need A Break And Why?

- Carers can have a great need for respite from the situation that they are in.
- The respite they need may not always correspond to users' needs for respite care.

How Do We Feel About Carers Needing A Break?

- Although some people can feel guilty about the fact that their carers need a break, most believe that it is a part of life to which people need to adapt and accept.

Alternative Views About When Respite Is And Isn't Needed

A small number of people looked at respite in the following ways:

Some saw illness in terms of a spectrum -

At one end of the spectrum a person is very ill and life a constant struggle, even simple tasks become unmanageable and distress is a constant feature. For such people hospitalisation is an ever present possibility and respite from their situation, as a positive alternative to hospital, would be welcome as a part of their treatment.

Other people are at the other end of the spectrum and are coming out of a period of their lives that have been dominated by illness. Life is looking up but they have had little time to enjoy themselves or relax and have great problems with their self confidence and motivation.

For such people respite care could act as a bridge to a new and more positive life and would also be welcome.

Then in the middle there are some people who are maintaining a life but with great difficulty. For some of these people change and holidays and breaks could be more than they could cope with, both because it requires a great effort to organise but also because facing a 'better' life away from home just serves to remind them how hard life at home is. This pointed to the agony of situations where home life is almost insupportable and changes in routine only serve to point out how fragile their life has become.

A small number of others who thought that respite care, especially any respite care that could be seen as enjoyable, should not be an option.

This was for two reasons:

Many people with a mental illness are barely tolerated in their communities. If they were seen to be getting breaks that other people weren't then the community would react even more negatively to them.

"People still have a misapprehension that hospital or respite is about having a good time."

The other related reason was that many people live in difficult situations (for instance those who are in long term unemployment or those on very low incomes). They cannot afford breaks, and do not expect them, and therefore why should people with a mental illness? Can they demonstrate that they have a greater need than any other disadvantaged group?

People were also keen to say that everyone needs a break from their environment whether they are ill or disabled or not, and that one of the main problems was that some sections of the community did not have this opportunity.

What Should People Get Out Of A Respite Care Facility?

People wished to:

1. recharge themselves
2. feel refreshed
3. get peace of mind
4. become de-stressed
5. have nothing to worry about
6. be able to talk things through with another person
7. be able to reflect on their situation and how to cope when they get back to it
8. get a break
9. get away from pressure and their home situation
10. give their carers a break
11. look at the problem they are escaping from along with the support of staff at the centre
12. escape from their problems
13. gain insight into how they are managing
14. get back to how life used to be
15. have help with coping
16. have a review of their treatment
17. get used to life again
18. jumpstart into a new way of living
19. have something to look forward to
20. have help with both their health and social circumstances
21. increase their confidence
22. have a chance to learn

WHAT SHOULD HAPPEN IN RESPITE CARE?

People would like:

1. to rest
2. to sleep
3. to be looked after
4. to be left to their own devices to a certain degree, and to do what they want when they want
5. minimum rules and order – just enough to keep the place safe and functioning
6. nothing should happen at all
7. there should be gentle activities which you might be gently prodded into doing
8. it would be possible to opt in or out of activities
9. to be taken out, treated, do things, enjoy ourselves – a real break
10. there should be good food
11. an opportunity for arts and crafts
12. physical activity
13. anxiety management and other groups
14. self management courses
15. people there to do things for you when this is needed
16. little pressure
17. it should not be authoritarian or controlling (although routine is important)
18. there should be games, activities and distractions
19. being able to get to know people with similar illnesses
20. to get to know people and know that they are there for you when you need them
21. it should provide security and safety
22. it should be enjoyable
23. no uniforms
24. there should be access to a library and computers
25. there would be space and peace
26. it would be a gentle place
27. it would be an attractive place and would be well equipped
28. there should be access to people who are friendly and also know what they are doing.
29. there should be ways in which you can express your anger and frustration – perhaps a punch bag

ACKNOWLEDGEMENTS

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

For more information about HUG, or an information pack, call:

**Graham Morgan
Highland Users Group
c/o Highland Community Care Forum
Highland House
20 Longman Road
Inverness IV1 1 RY**

**Telephone: 01463 718817
Fax: 01463 718818
E-mail: hug@hccf.org.uk**

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