



MEDI CATION FOR PEOPLE WITH MENTAL HEALTH PROBLEMS

The views of 73 people on medication:
What we think of it, the information we get, the people who provide it
and other medication issues

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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.
- ◆ 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 cooperation between agencies concerned with mental health.

INTRODUCTION

In 2004 the HUG committee (the Round Table) was approached by the Highland Pharmacy Service to discuss pharmacy services as part of their review of pharmacy across the Highland region. The discussion we had, prompted us to hold our own consultation with our members.

We held meetings in ten of our branches and involved 73 people.

We also held a further meeting with 8 members of our Round Table to look at the contents of our previous report on medication, which was published in 1996, and to see how much of it was still relevant. This report is a distillation of these meetings.

Medication and mental health is a subject that we often talk about. Some of us feel that without medication we would either be in hospital or would not have survived our illness. Others see it as an intrusion into our lives and sense of self that we deeply resent, and would rather do without. Some of us have just got used to medication as part of our normal routine.

It is a subject that is coloured by many different contexts. Sometimes we hear of the sad tragedies of people who have died at the hands of people with a mental illness, and hear the calls that it should be much easier to compel us to take medication both for our own health, and the safety of those around us. At other times, we hear about the profits drug companies make and become aware that the medication we take is big business, and surrounded by a myriad of ethical issues to do with the information and safeguards around the medication. Then there is the confusion about the balance between drug, talking treatments and other therapies, the pressure we find ourselves under to take medication and the lack of suitable alternatives.

This report looks briefly at all these issues as well as the service that we get from pharmacists.

MEDICATION ISSUES

ARE WE TOLD ABOUT THE EFFECTS OF OUR MEDICATION?

When we first asked this question the immediate reaction was that we are given very little information. We felt some anger at the shortage of information that we had, and sometimes felt that this was deliberately withheld from us or, at least, was not offered. We felt that we were left to discover information on our own when, ideally, we would have it volunteered and explained without us needing to seize the initiative. We also felt that we didn't really know where to go to find out more if we weren't satisfied with the leaflets that we were given.

On further reflection, however, many of us felt that information provision had increased and improved greatly over the last few years. In the relatively recent past, we felt that information was generally poorly provided and rarely volunteered.

Although the information leaflets in packs of medication was sometimes in a very small font, there was a feeling that the language used and the information provided was much better and easier to understand than in the past. Some of us found that if we asked for assistance, this was provided by a variety of people including psychiatrists, pharmacists or community psychiatric nurses. Sometimes this was very helpful; the professionals listened carefully, gave us time and provided information about our medication without us asking.

Some of us had received a great deal of literature when contemplating changes in medication, which was often very helpful. This, and general explanations offered to us, helped us make decisions about the medication that we take.

We talked about being in hospital. Some of us had had excellent assistance, which included having our medication explained to us by our nurses. These nurses also answered any worries or objections that we may have had about medication. We were very happy with this, as well as with the pharmacy service.

At home, however, it can still be hard to get information and, although the GP may try to help, they often have limited knowledge. They may seem to be the only source of advice (especially in rural areas). There are some GPs who have explained side effects and medication very clearly and, when they have lacked knowledge, have admitted this and then sought out the answers for us.

Some of us talked about not having any say over our medication when under a section, but that once this was lifted we were given much more control. Sometimes we discussed the unpleasantness of the side effects with our psychiatrists, and were pleased to see alternatives being offered.

We thought that the information given to us should vary with the person concerned, and with individual circumstances. There was an idea that a booklet could be developed that points out the sort of questions anyone of us might ask about our medication when we are seeing a pharmacist or doctor. This would make it easier to ask and remember questions and the booklet could have space for answers. It could also be used to record side effects and worries.

Generally, a guide that explains who to ask what, and when, may assist us.

Some of us felt that we needed to point out that mental illness is something that we can recover from, and that this needs emphasised at the beginning of our treatment. We should also be clear that we may not be on medication indefinitely. However we wanted to make the point that far from medication being always a bad thing, that we could sometimes regard its use as a sign of self care and help. Just as some people take vitamin pills for their health, so, on occasion do we take medication for our mental health.

DO WE NEED TO TAKE MEDICATION?

Most of us agree that we do need to take medication, and that it can make our lives manageable. We also felt, however, that the need for medication varied with the severity of our illnesses.

"I would love to be free of medication. I would give anything to be free of it, but the fear of previous illness stops this"

"I've been on the same medication for 10-15 years, and feel happy about it because it helps"

We also felt that medication on its own was not the only answer, but too often found that it was almost all that was on offer. We were especially keen to see greater access to alternative and complementary therapies such as talk therapies, especially cognitive behavioural therapy, as alternatives or additions to medication. Occasionally, we asked about alternatives such as fish oils or techniques such as relaxation, stress management or Reiki, and were met with very negative attitudes from some professionals. This made us feel guilty and diminished our confidence.

A few of us had become addicted to medication, especially to some of the older medicines. Those who had experienced this felt very much damaged by it.

"I never wanted medication and ended up taking it for 30 years. It destroyed a large part of my life."

We did worry that we can get used to medication, and that we may become so used to it that we don't look at the option of trying to live drug free. Medication may keep us stable, but equally it may come to represent something that we rely on unnecessarily.

Some of us just think medication is something that we should avoid.

We also worried about whether or not the cost of prescribing medication influenced what we are offered.

WHY DON'T WE LIKE TAKING MEDICATION?

The overwhelming reason for disliking medication was because of the side effects it produces. The main side effect that was mentioned in all groups was the considerable weight gain that many people had experienced. Other side effects commonly mentioned were: "feeling slowed down, 'zombified', sedated and drowsy." Some of us also had eye sight problems.

Other reasons we disliked medication were more about how we viewed medication. Some of us felt that it made us dependant or even controlled,

not only by the chemicals, but also by the professionals who prescribe them. It seemed to us that this diminishes our autonomy and sense of self. Some of us have been on medication and well for a number of years. Are we now better? If we are, is this because of the medication? Or perhaps we should contemplate trying without it?

The routine of taking medication everyday caused resentment, not least because every time we took a pill it reminded us that we are ill, but also because some of us do not live the sort of life that respects the routine taking medication imposes. We may feel that having to take medication, maybe for life, is a sign that we have failed in our lives; it means accepting that we are ill. We question whether or not the changes it produces in us are changes that we can accept. How much of 'us' is left if we have to take a substance that alters mood and thought?

The subject of medication is also connected to our personal or cultural beliefs towards pharmaceuticals. Some of us, in common with much of the rest of society, do not approve of drug companies making such large profits in this area of health. Others find it hard to accept animal testing, and others because of their religious or cultural beliefs, cannot willingly accept medication.

Sometimes not taking medication is connected to stigma. Friends and family may find it hard to believe in our illness, and find it hard to accept that there is a need for medication.

We also had more practical worries. What if we come off medication? Will there be withdrawal effects? Can we cope without it? Might we get addicted? Will we get ill again? Some of us don't like to take medication because it may affect our ability to work, use machinery or to drive. It also stops some of us from drinking alcohol, which doesn't please those of us who like to drink. Many of us find it hard to get up in the mornings when on medication, which is also resented.

Some of us feel that medication becomes part of maintaining us in a state of diminished wellbeing. If we could look to the future, or examine causes and changes to our lives, then we might feel that we have better prospects than if we just accept the need for medication and little else. Medication helps with symptoms, but is not often the cure. We need more than this limited option. It is a major part of our recovery, but not the only route we can take.

Some medications have a poor reputation, and come surrounded with a great deal of publicity. These 'scare stories' mean that we are reluctant to take the medication. Sometimes we are just not told enough, and feel unable to make an informed decision about whether or not to take it.

On a positive note, for some of us the step we take to stop taking medication is because we are genuinely better, and becomes a formal marker in our recovery.

WHAT HAPPENS WHEN WE CONTEMPLATE COMING OFF MEDICATION?

It is no longer the rule that professionals automatically discourage these ideas when we raise them. Many of us find it easy to get advice, and some of us feel supported in trying to live drug free, as well as equally supported to go back onto medication if we have difficulties managing without it.

It can be very helpful when professionals sit down with us and discuss our ideas and the reasons they have for asking us to take medication. Equally, it can be the opposite when they are dismissive and uninterested.

We did think there should be regular reviews of our medication, especially if we have been through a crisis or have been on the medication for a long time. It does feel to some of us that we can be put on medication with an assumption that this will continue indefinitely without room to pause and reconsider.

We can feel that people are suggesting actions with which we do not agree, and feel that we have little control over this. Even in such a situation, however, we can understand why this might happen occasionally if we have lost the ability to make informed decisions. The use of advance directives may help here.

Occasionally our experience with psychiatry itself puts us off. Bad experiences and controlling people can mean that we refuse to cooperate with a system that we feel takes away our autonomy. This can then result in a refusal to take medication.

There are still situations where we feel undue pressure is put on us over which we don't have enough control, and sometimes we end up being sectioned and admitted to hospital, and feel forced to take our medication. It was also mentioned quite frequently that some of us just choose to come off it without discussing the idea with anyone. We were more worried about the reaction of the doctor than of any problems that might occur in dealing with a reduction in medication.

It can feel as if we provoke fear and anxiety in professionals when wanting to come off medication. Sometimes it feels as if they don't listen and don't appreciate how much we dislike the medication. We can feel 'told off' as if we are children. We can sometimes face the argument that if we were diabetic then we would have no worries about long term medication, and so long term psychiatric medication should be viewed in the same light. This can be quite patronising.

However, some of us have come off medication against advice and, when we have been successful, have been praised by those who have helped us.

Sometimes there are alternatives to medication that we can try, but if they are not available then we are stuck with the status quo.

We felt that it was very important for our views to be listened to and respected. We need to know the different options, and need to act responsibly ourselves. We want our need to have control over what we put inside ourselves acknowledged. This wish now seems to be respected more and more often by professionals.

Some of us have had to have professional in-patient help in coming off medication because we have become addicted to it.

A different situation some of us encounter is that some doctors are quite suspicious of medication for people with mental health problems, and can be reluctant to prescribe it.

In hospital there sometimes seems to be an expectation on us to take the medication prescribed, or perhaps not to stay there if we object.

WHAT INFORMATION DO WE NEED TO BE TOLD?

Our main needs are to know:

- the side effects
- what will happen in the long-term
- what benefits we should expect in the short and long-term
- when to expect reviews
- what other medications might be useful
- the effect if we continue to drink
- what we can and can't do on medication, such as driving or using machinery
- explanations of the reasons for changes in dosage
- what the effect of medication is if we want to become pregnant or are breastfeeding
- what illness the medication is for
- the effect it has on us
- any dangerous side effects, for example becoming suicidal
- interactions with other medication
- what will happen if we stop taking it
- the science behind the medication

Alongside information on the medication, we should also be given information about key community and hospital sources of help if we encounter problems.

Overall, we need the information tailored to our individual circumstances. We need to speak with people who have an idea of what we need to know, and are ready to listen. This sort of partnership means that we need trusting and open relationships with the people who give us information. In addition, the information needs to be as accessible as possible in order for us to understand what we are being told easily. We also need to be cautious about being given too much and too graphic information. We can be very anxious about medication, and a zealous description of some of the more horrible side effects could cause great alarm. Of course we need to temper this with the information that we should all have a right to receive.

WHO SHOULD WE GET INFORMATION FROM?

Community psychiatric nurses can be very good, as can pharmacists at New Craigs and in the community, although not everyone would naturally think of using their local chemist.

Doctors would seem to be an obvious choice and often are, but sometimes GPs don't have enough knowledge and sometimes are hard to talk to about mental health. Some psychiatrists don't seem to have the time or we have to wait a long time to see them, so we sometimes try to avoid bothering them.

We also get information from people working in drop in centres and from our fellow users, and more and more of us are getting information directly from the internet. It was suggested that websites (such as the NHS Highland website) should have this sort of health information on it, and that we should have information about where to find reliable websites.

Advocacy services may help us if we are trying to get information.

Anyone who works in mental health can provide information. Some are good because we know and trust them well; others because they are experts in the subject.

The training that the New Craigs Pharmacy Department has done on medication with professionals has been very well received, and should make our workers in the field of mental health clearer about how to pass on information.

There was also a suggestion that a telephone helpline could be useful.

Some of us still find it hard to get reliable information, and don't really know who to turn to.

TRAVELLING FOR MEDICATION

This can be a problem for two reasons. Firstly, it can be difficult to get to the chemists because of the distance or poor public transport (one person had to travel 14 miles to get their prescription), and some of us

have to use a taxi to get our medication. Secondly, when we are ill we may not be able get out of the house to pick up medication.

This problem was sometimes solved in one of two ways. Mental health professionals provided medication and took it to us, or pharmacists delivered the medication either to us or to a local pick up point.

A point was made that in some more urban areas it was possible to get medication any day of the week, and that the Highlands didn't compare well in this respect.

MEDICATION SCARES

This caused a lot of anxiety in HUG. The recent controversy over Seroxat was very public and caused a great deal of anxiety to our members. It resulted in some of us phoning the television companies in order to say how much the medication had helped them, but with others the worries it caused meant that some members refused to go on such medication.

We worried about the power of pharmaceutical companies and their need to promote a positive image to their medicines, even in the face of seemingly irrefutable evidence that they could cause very damaging side effects to people. Many of us felt deeply wary of them, and had little confidence that the companies would do anything more than the minimum about revealing and responding to news of the damaging effects of medication.

Some of us felt that little credence was given to the stories of side effects as reported by us as users, and that the companies did not respond to scares seriously. We also worried about how influenced pharmacists and doctors were by the drug companies. Did they gain by selling or prescribing certain medications? Some of us thought so.

We urged both doctors and pharmacists to be open, direct, informative, honest and, if possible, reassuring when faced with such scares, and to avoid being sucked into establishment responses to the stories.

However, a small number of us said that in this country there is a general anti-medication culture which can, at times, be damaging to people who are helped by medication.

MONITORING OF MEDICATION SUCH AS LITHIUM AND CLOZAPINE

Some of us were quite content with the monitoring of such drugs, but not everyone was.

For some of us regular monitoring didn't happen. In fact, in one situation it was only the intervention of the pharmacist that allowed any blood test of lithium levels to occur. Some of us found that blood tests were sometimes not offered routinely, and that we had to ask for them.

Some of us were also unsure how long after taking medication, or eating food, blood tests should be taken.

Many of us were not aware of how much monitoring was needed for our drugs, and others had suffered through ignorance. One person is experiencing kidney damage as a result of mixed messages about how to keep healthy on their medication.

WHAT ABOUT ALTERNATIVES TO MEDICATION?

Many of us would like access to alternatives or complementary services to medication for instance treatments ranging from specialised psychological services to counselling and relaxation courses. We would find it very helpful to find out about these from a skilled person at the chemists.

We would also like to know about less conventional remedies and treatments such as homeopathy and other treatments. It would be good to have information on these at the chemists too. However, some of us do not appreciate such remedies and are worried that they may interfere with our medication. We also felt that the chemist may not have enough expertise in this area to give sound advice.

Some of us also said that there should be more access to alternatives to medication in the form of NHS prescriptions. For example, prescriptions for exercise and access to the range of private treatments that are not presently available on the NHS, and which most of us can't afford. There should also be access to relaxation facilities such as snoozelum rooms and other complementary and alternative therapies.

PHARMACY SERVICES

NEW CRAIGS PHARMACY SERVICE

Nearly everyone who had heard of the New Craigs Pharmacy Service had considerable praise for it.

We felt that it was excellent. It provided good easy to read leaflets, and arranged individual consultations about present and new medication both in the department and on our own wards.

They worked alongside the psychiatrist, and then we discussed the issue together. This sort of partnership was first rate.

They were generally quick and efficient about supplying medication. Some of us phoned them when we had queries, and found them polite and helpful and always ready to spend time on our questions.

However, some of us, especially those of us who had not been in hospital and who live some distance away, were unaware of what they did and had no comment to give. We said they should expand to give a wider knowledge of their service both amongst users and professionals, and that the information they provide needed to be promoted and volunteered rather than met by requests. There was also some comment that leaflets were not included in medication packs being handed out at New Craigs. We thought there should be.

The Pharmacy Department was due to visit one of the drop-in centres at the time of our meetings and people were looking forward to this. Feedback about the training they provide was also very positive.

"they were extremely helpful ... they told me more about drugs and what is going on than the doctor. The side effects, how it works, why I was taking it - they volunteered the information rather than us having to ask it..... it was easy to see them quickly.... I learnt more about my medication from them than anyone else."

"I was offered the choice of two new mood stabilisers with printed sheets provided from the Pharmacy listing possible side effects. This was very useful, it was also suggested that I could get more information from the Pharmacy if I wanted to."

"they were really excellent; they gave me all the bump it was really really good – I didn't really want to know it all but it was still good and helped me with self medication and taking control."

COMMUNITY PHARMACISTS

We were generally positive about local chemists, and found the pharmacists to be very helpful, informative and professional. We felt that they often knew us well and picked up on any changes in medication, checked prescriptions for new doses and sometimes picked up on mistakes in doctors' prescriptions.

The Community Pharmacists can be the first and most regular contact we have, and may be the first to notice any problems we are having. They can also pick up on missed prescriptions and give us a friendly reminder about them.

"If you phone they do have specialist knowledge, they should link together with the GP and the psychiatrist."

" they can pick up on mistakes from the doctors, especially if they know you. Boots were excellent. I was in pain and given the wrong medication; an effect was hallucinations. The pharmacist picked up on it and explained things, which was very reassuring."

However, we can sometimes be self-conscious when giving in our prescription, and may be very aware that they know what is wrong with us from our prescription. It can also be hard to ask for advice as the chemist is such a public environment, and there don't appear to be private consulting rooms. Some of us get over this by phoning up to ask questions and, therefore, achieving some privacy. Some of us thought pharmacists might benefit from mental health awareness training to help them learn about the sort of lives we lead.

"Pharmacists are good, but not all have a good attitude"

" I would ask at New Craigs, but not at a local chemist – it is far too open and too public."

Many of us thought pharmacists would be the best people to get information on medication from. They are the experts, are easy to see

and have more time. However, some of us preferred the idea of approaching doctors instead, and were worried that advice on medication might detract or conflict with health advice from doctors.

"Where there are chemists – they can provide information and advice that we might not get from a doctor."

As with any profession, however, we didn't get on with all pharmacists, and found some abrupt, unhelpful and unwilling to offer information. We sometimes don't know what we can or should ask of them and a few of us saw them as just people who handed out medication, and couldn't think of any role that they should have in our lives beyond this.

WHAT IS A 'LOCAL' PHARMACIST?

In an area such as the Highlands, the concept of a local pharmacist can be very important. Indeed, in some areas, there are no pharmacists.

We thought that the definition of a local pharmacist is two fold:

1. They are near to us geographically and are relatively easy to get to by foot or by public transport.
2. They are so much a part of the local community that they know us by sight or name, and will pick up on any problems we encounter with our medication or any unusual requests we make. If necessary, we can contact them easily about issues to do with our health and medication. (This is usually very good, but can on occasion feel quite embarrassing. We can be very self-conscious about the medication we have been prescribed and what members of the local community think about it.)

Being local can also mean that there is only one option for us to use. This is not so good if we don't approve of our particular chemist.

Some of us also felt there was a need for local chemists rather than national chains (although many of us had also had a good service from these too). We felt that there was a better atmosphere in the local chemists.

DISPENSING DOCTORS

In some areas there are no pharmacists, instead the doctors provide the medication.

We asked about this, and had two reactions. Doctors can be very helpful and very accessible; it can be much more convenient to use them for medication. However, picking up medication and fitting in with surgery hours is not always easy.

On the other hand, there is some worry that the doctors may not always be as up-to-date on information about medication as the pharmacists.

SHOULD THERE BE LINKS BETWEEN THE PHARMACIST AND THE COMMUNITY MENTAL HEALTH TEAM?

Most of us thought that this could be a good idea, but some of us worried about how much information people should get who are, in some ways, on the periphery of our care. We also felt that the teams could benefit from the training that pharmacists sometimes provide.

INVOLVEMENT IN WARD ROUNDS AND CASE REVIEWS

We wondered if the pharmacists could be useful in these situations, and found that they were routinely involved in ward rounds at New Craigs and sometimes in Care Programme approach reviews.

Everyone who had experienced this said that this was very helpful, and most of us said that the presence of pharmacists at such meetings should be encouraged. A few of us worried that we might begin to feel overly controlled if too many professionals attended such meetings.

We also thought occasional surgeries in places such as drop-in centres could also be good.

REGISTERING WITH OUR LOCAL PHARMACIST

Most of us agreed that, as long as this was a voluntary practice, registering with our pharmacist and giving them some basic details about us, could enhance our care and act positively to protect our mental health.

Again, however, a few of us worried that too much information would be spread about us, and we would find ourselves monitored too much by other people. We also felt that advance statements could help with this.

A few of us are already informally registered with chemists like Boots, and find it very helpful.

WHAT WE NEED FROM A PHARMACIST

Pharmacists already provide advice and information, and this is welcomed by those confident enough to ask for it, but some work still needs done to make it easy to ask for advice. They can be very good at giving us insight into medication and its side effects, the reasons we are taking it and what not to mix it with, which all assists us to be responsible in how we view our medication.

It could also be good if they could have resources on general health matters as well as information about community facilities. Information about nutrition and its effect and connection with psychiatric medication would also be useful.

They can also be an early warning system for when our life is breaking down. They can notice signs of illness or missed prescriptions and then give either friendly reminders or even intervene to get us help. This would be welcome to many of us as long as we don't come to feel 'policed' by another professional.

Some of us are happier seeking information from specialist services such as the one in New Craigs.

The seating areas that we use to wait for medication could in some cases be made more attractive, and private rooms may help with embarrassing questions. We also need to be sure that the pharmacists are approachable and accessible and easy to ask questions of. We sometimes find it hard to

Speak out and, if they appear rushed and busy, we may not ask questions that are important to us. We need to be sure that they will listen to us, and not instantly assume we are at fault if we are encountering difficulties. We also need to be sure of confidentiality, asking the first awkward question at the counter often means that we break our own privacy.

Ideally, the doctor will also have explained our medication thoroughly at the time of prescribing, and will volunteer information if new and more effective medications come on to the market.

A medication helpline may be useful as a convenient and accessible form of advice and information.

Although we are keen to enhance the pharmacist's role in giving information, some of us were also hesitant. We didn't want to push them into giving information that may conflict with the doctors, or where they may lack the skills to provide it. Some of us were so worried about this that we said that they should give no health advice at all.

A GUIDE TO WHAT A PHARMACIST DOES

We all agreed that a guide would be useful. Many of us felt quite ignorant about what we should expect from a pharmacy service.

PRESCRIPTIONS

PRESCRIPTION CHARGES

Most of us thought that if we are on long-term medication, then we should not have to pay prescription charges just as people taking medication for other long-term illnesses (such as diabetes) don't pay charges. This is even more important for those taking multiple prescriptions. Some of us thought all prescriptions should be free for anyone under a section.

The prepayment card, which gives a discount off prescriptions, is very good for some people.

HOW ABOUT WEEKLY PRESCRIPTIONS?

Some of our members are put on to weekly prescriptions, usually because they are considered to be a suicide risk and need to be kept from too much easily accessible medication. For some this is fine and causes no problems.

In retrospect, most of us said that this was the best thing to do, but that at the time some of us had resented the process and had felt overly controlled and monitored.

A very small number of us had felt exposed to negative attitudes from the pharmacists. For example, being told off if we were a day late, being made to feel a nuisance and having the fact that we were on a weekly prescription announced publicly, which we found very embarrassing.

The delay in getting the prescription to the pharmacist can cause problems initially, and additional problems occur if we intend to be away from home for over a week.

SHOULD REPEAT PRESCRIPTIONS GO DIRECT TO THE PHARMACIST?

Many surgeries now send prescriptions direct to the pharmacist, which means that we just need one trip to get our medication.

Those of us who experience this find it much more convenient; our only major worry being that we might cut the doctor out of the process of monitoring and review. We need to be sure that our doctors are fully aware of our condition and the medication. They may lose sight of this if we never go to the surgery.

SHOULD WE BE ABLE TO ORDER REPEAT PRESCRIPTIONS BY EMAIL OR BY ANSWER PHONE?

The procedure of ordering medication can be cumbersome, and may require people to phone the doctors at inconvenient times. We thought that as long as the technology worked, ordering medication on an answer phone or by email may make the process easier for everyone.

ANY OTHER VIEWS ON MEDICATION

ALTERNATIVES

We strongly feel that there is a need for a range of treatments, and that these treatments need to be available and affordable or free.

The whole range of talking therapies can be very effective, and yet the wait to see a psychologist can be up to 18 months. Alternative and complementary treatments such as stress reduction, massage, reflexology or fish oils are appealing for some, but not easy to afford and in some areas are available free on the NHS and in others not.

Less obvious therapies such as exercise prescriptions could also be good but are also only available in some areas.

PREGNANCY AND CHILDREN

Some of us have had to come off our medication in order to have children. Sometimes this is successful, but on other occasions it has caused relapse and a decision not to have children. This can cause great trauma.

There was a call for better information about medication and pregnancy.

COST

We worry that some GPs are encouraged to use cheaper drugs rather than the best option, but didn't know whether or not this was true.

SELF-MEDICATION WHEN AN IN-PATIENT

We discussed whether it would be a good idea to self-medicate when we are in hospital. Whilst we said that this should vary from situation to situation and person to person, we did worry about the idea and appreciated that when feeling vulnerable passing control to our doctors and nurses would often be the best option.

TRAVELLING

There can be problems in obtaining medication when travelling, especially abroad.

SELF - INTEREST

We wondered how much doctors are swayed in their prescribing by drug companies, and how much they are influenced to provide other treatments such as talking therapies. It seemed to us that there maybe some form of commercial incentive to prescribe drugs as opposed to other therapies.

We worried about the influence of drug companies and the comparatively small incentive to look at other treatments which so many of us felt could be of benefit to us.

COMMUNICATION

Sometimes we feel that the time it takes for a psychiatrist to let the GP know about changes in medication can delay the care we get.

SECTIONING

Some people talked about how powerless they felt when made to take medication under a section, and equally how horrible it was for them to be forcibly medicated when they refused it.

CONCLUSION

The information that we get about our medication has improved greatly in recent years, but we are not all content that we are given enough information about it, although many professionals (including pharmacists and doctors) do now routinely volunteer information and advice.

Despite the fact that many of us do agree to the need for medication, we have many reasons for resisting it. In the past, it would have been very common for these comments to have been dismissed, but nowadays we feel that our concerns are being treated much more seriously.

The New Craigs Pharmacy Department was highly praised by the people who have used it, and community pharmacists were seen as very helpful too.

It may be an idea to link community pharmacists with other professionals concerned with our care, and to give them the resources to increase health information provision at the chemists.

There are a number of measures that many of us think could enhance the role of the community pharmacist, which include registering with them, having access to advice in privacy as well as making the prescribing of medication easier.

Whilst most of us agree with medication, we also have strong feelings that it is not a solution on its own; a number of other options including conventional and complementary treatments could also greatly enhance our lives.

RECOMMENDATIONS

1. Professionals should volunteer to explain the medication we are prescribed at the start, during treatment and when any changes in treatment occur.
2. The New Craigs Pharmacy Service is greatly appreciated, and should be supported in the advice and information it provides.
3. It would be good to provide information clinics on medication in various community settings.
4. We would like to see leaflets provided in the packs of medication that we get from hospital.
5. It would be good to provide reference books in places that we meet.
6. Prescription charges for people on long-term medication should be free.
7. The help of an advocate could be useful when discussing our concerns.
8. The use of advance directives can also help.
9. Community pharmacists could provide a range of health related services such as information and possibly advice.
10. It would be helpful to know which websites provide reliable advice.
11. It is useful for users to be in the centre of decisions concerning their medication.
12. We need information tailored to our circumstances.
13. When people cannot travel for medication they may need assistance in getting it.
14. We need pharmacists and doctors to be open and honest when dealing with medication scares.
15. The pharmacist could usefully link with community mental health teams when dealing with our care.
16. It may be a good idea to register with pharmacists.
17. We could be helped by having the role of pharmacists explained in a guide.
18. Prescriptions may be more easily accessed by using answer phones or emails.
19. We need to look to alternatives to medication.
20. We need improved information on medication and pregnancy.

APPENDIX 1

PERSONAL TESTIMONIES

1. MEDICATION IN THE COMMUNITY

For many years I had been having my medication given to me by injection. I think the initial reason for this was because I was reluctant to take medication at all and in this way they could be sure that I would take it.

I didn't like injections. Not only did they make me sore for a few days after but also they were undignified and gave me side effects that I didn't like. I had often raised my dislike of medication but I think it had become a bit routine. I raised the issue and didn't really expect anything to happen as result.

One day however, I became aware of a new medication and requested that medication with slightly more vigour and was also listened to more intently.

We agreed that the option was realistic, the drug was explained to me and what its likely effect would be.

My psychiatrist arranged for the pharmacy department to send information on the medication I had requested, and ones similar to it, to my home. The leaflets were clear and helpful and helped my make my mind up.

At the next meeting, I told my doctor which one I preferred and he accepted this and started to make arrangements to handle the transfer to the new drugs.

We had a period where I was on both medications. At this time I saw the doctor quite frequently to check that everything was going well.

I managed the transition fine and felt very satisfied with my new medication – I felt less slow, less jittery, my legs had stopped shaking and yet I was still keeping well.

2. MEDICATION IN HOSPITAL

I had changed to a new and greatly improved medication and to start with it was absolutely fantastic.

I felt alert and dynamic for the first time in years. I had this feeling of vibrancy and energy and vim. I paid more attention to my son and sought out things to do with him. My wife said that for the first time in a decade that she had found the husband that she had lost when I had become ill.

It was really fantastic, but along with this re-engagement with life came a lack of engagement with sleep. After a few weeks of only getting a couple of hours sleep a night we began to worry a little and made some tentative enquiries about whether this should be happening. And it is at these times that you realise how slow the system can be as we didn't really get any answers or advice about what to do.

After another two weeks when sleep became even more rare and the night hours beckoned in their lonely way, some of the thoughts I had been having began to build their own meanings and logic and my reality became slightly skewed.

I didn't tell anyone what I was thinking and I don't know why I didn't. It was just hard to admit to the thoughts of self harm and damage and the spirits and the light. I couldn't face anyone with my feelings.

Then in what seemed a flurry of activity, I had seen a psychiatrist and been given the option of going into hospital voluntarily or being sectioned.

I didn't really know what to think as it had been years since I was last in hospital but my wife was devastated.

The very first thing they wanted to do was to put me back on to my old medication and at first I couldn't face this. There had been a joy in the last few weeks as well as exhaustion, I couldn't bear the thought of being back on a medication that shut me down again, that closed my vision of the world to a partial one.

I do now understand why I had to go back on the medication, though I greatly regret it. The professionals did not insist on me taking the medication. They were patient and kept on explaining why they thought I

should take the drugs and I kept on crying because I thought it would ruin my life.

Eventually I did agree to take the medication and even took some other relaxing drug to calm me down when I was agitated. I refused the sleeping pills though, and that was accepted.

Everyone from psychiatrist to nurse to pharmacist took time to listen to me, to my anger, my fear and my disappointment. I could talk about it and did in the ward rounds and also saw people (especially the pharmacist) outside of these times.

They stuck to their view that I had to take the old medication again but they did really listen to my concerns and respected my views and explained why they thought what had happened had happened. It didn't stop my huge disappointment. At some times in those days I thought it would be better to be dead than spend however many more decades having to take this drug. Now, in retrospect, it seems good that I did. I have lost most of my symptoms and life is normal again but that taste, that glimpse of what life can really feel like – in a way I wish I had never had it. It makes me feel very sad and regretful.

3. ORDERING REPEAT PRESCRIPTIONS

My GP surgery is only a small 3 doctor practice but they have been running a successful email repeat prescription service for 2 years. To order my repeat prescription, I simply send an email with my name, date of birth and medication to a dedicated email address which is printed on every repeat prescription slip. It is just like online shopping - they send me a receipt email and my medication arrives at my pharmacy 48 hours later! I find this really convenient and I am less likely to forget to order my medication as I can order at any time, even when it's 10pm and I discover that I only have a few tablets left. The email prescription service is excellent and I think it should be available at all GP surgeries.

APPENDIX 2

REACTION TO THIS REPORT

We have received the following comments on this report which we thought would interest our readers:

".... We were impressed by your willingness to undertake the work required to provide information to assist in the development of pharmaceutical services in NHS Highland. This is an excellent piece of work, which your organisation can be proud to have produced. It will be used to inform the development of these services. It was interesting and reassuring for us to see that many of the issues raised by HUG are already incorporated into the 'Right Medicine – strategy for Pharmaceutical Care in NHS Scotland and that NHS policy closely matches the patient/public perspective...."

Mary Morton Acting Chief Pharmacist (primary care) NHS Highland.

"..... the report is balanced, very constructive, well structured and very well presented. Its contents will be extremely helpful in informing health care professionals about medication for people with mental health problems and the services which we provide from the perspective of the users. As we review and integrate pharmacy services across NHS Highland we hope we will be able to take account of your report and where possible implement its recommendations....

... of course your report has relevance to all concerned with the care of people with mental health problems. We would hope that you would consider widespread distribution of your report to those groups and individuals whose practice may benefit from a knowledge of users' perspectives.

You have provided us with important information which should enable us to improve the services which we offer to people with mental health problems in the Highlands."

John Cromarty, Chief Pharmacist, Highland Acute Hospitals Pharmacy Department.

"... I found your report fascinating and will be happy to circulate it on final publication."

Jackie Agnew Service Manager Mental Health and Learning Disability,
NHS Highland.

"... we have in the past made service delivery changes based on the content of a HUG report and I envisage further changes will be a consequence of this report.

The report draws reasoned conclusions and makes practical recommendations on medication, prescriptions and pharmacy service issues. A recurring theme in the report that I would particularly endorse concerns the significant potential existing for community pharmacists to make further contributions to enhancing patient care..."

Tom Shaw (principle pharmacist mental health) NHS Highland

"... the report reflects the many and varied issues and experiences of patients about their medication. The key messages are very clear with communication and the opportunity for informed decision making appropriately highlighted. I am sure that there is a lot of work to be done in promoting greater shared understanding and treatment goals.

It was good to see the hospital pharmacy department get the recognition they so richly deserve."

Dr Chris Macgregor , Clinical Lead New Craigs.

"I am really happy with the medication report – it is excellent it covers everything."

HUG member

ACKNOWLEDGEMENTS

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

(Please feel free to photocopy this report)

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

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

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