



Mental Health : What's the Story?

Twenty-one people who have used mental health services in the Lomond area share their experiences

A user-led research project by Lomond & Argyll
Advocacy Service and Dumbarton & District
Mental Health Forum

Mental Health: What's the Story?

ACKNOWLEDGEMENTS

One person in four will experience mental health problems at some stage in their life. Behind every statistic is an individual with a personal story.

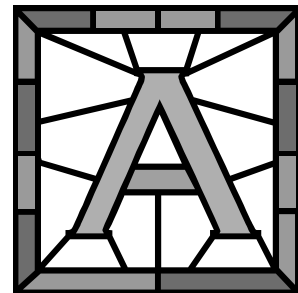
We would like to thank the twenty one people who have used mental health services in the Lomond area and who agreed to tell their stories and share their experience as part of this user-led research project. Their stories were always interesting and informative, often intimate and inspiring, sometimes humorous and sometimes harrowing. They are all "Experts by Experience".

Lomond & Argyll Advocacy Service and Dumbarton & District Mental Health Forum would also like to acknowledge the financial support they received from NHS Argyll & Clyde, which made the project possible, the assistance of West Dunbartonshire Council, and, most of all, the small group of individuals - themselves users of mental health services - who worked so hard to conduct the research and

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PART ONE:

The Background

Introduction

During 2004 Lomond & Argyll Advocacy Service, in partnership with Dumbarton & District Mental Health Forum, facilitated a user-led project to research the experiences of people who have used mental health services in the Lomond locality. We believe that no one knows better than people who use these services what works and what doesn't and how things could be made better. Our intention was to produce a report which would highlight the real experiences of people who have used mental health services in the Lomond area, their common concerns and ideas for improvements.

User Involvement

In recent years, the value of working to involve users of mental health services more – both individually in decisions about their own care and treatment and collectively in contributing to the planning, provision, management and monitoring of services – has been recognised and has attracted a higher priority.

This is partly the result of increasing action by service users and user groups themselves and partly because of the commitment to user involvement that has underpinned a range of initiatives by government and local health and social work services.

In December 2000 *"Our National Health: A plan for action, a plan for change"* was launched. The plan outlines how the Scottish Executive proposes to improve the health of people in Scotland, deliver high-quality health and social care services, and address inequalities in health more effectively. The plan recognises that to achieve these aims there needs to be a cultural change in the way in which services interact with the people they serve and that it is no longer good enough to simply do things *to* people; a modern health service must do things *with* the people it serves.

"We want to work with the NHS to ensure that a patient focus is embedded in the culture. To make this happen we will ensure that listening, understanding and acting on the views of local communities, patients

and carers is given the same priority as clinical standards and financial performance.”

The Scottish Executive
Our National Health : A plan for action, a plan for change (p50)

The idea of patient and public involvement in health and social care services is not entirely new but over recent years has, undoubtedly, received a much higher priority. In the old days doctor knew best, health planners knew best and the government knew best. But times are changing.

A brief history of the development of user involvement in Scottish Health Services

- 1948 The NHS is born but focuses on individual patients while local authorities retain responsibility for public health matters. Limited involvement of individuals**
- 1960s Series of public scandals regarding older people, people with mental health problems and people with learning difficulties raises public awareness of malpractice and poor quality services**
- 1968 Medicines Act gives patients the right to know names of prescribed drugs**
- 1974 Health services reform establishes the Health Councils and the post of Health Commissioner to deal with non –clinical complaints**
- 1980s Sees the development of community health and public health movements, and growth of user**

and advocacy movements. User-led campaigns mean user involvement becomes more developed in certain areas

1983 "Griffiths Report" is critical of the management approach and insularity of NHS managers, and urges greater sensitivity to customers. Introduction of competition, contracts and the "market model"

1990s Growing interest in consumerism and quality within NHS. The NHS and Community Care (Scotland) Act 1990 emphasises joint working and user and carer involvement in health and social care

1991 The Patient's Charter introduces new rights for patients

1997 Designed to Care White Paper introduces vision of "a patient focused service built on partnership". Also launched idea of Healthy Living Centres acknowledging the wider influences on health and a new public health agenda

1999 Towards a Healthier Scotland White Paper - recognises the need to tackle inequalities through action on 3 levels: life circumstances, lifestyles and health topics

2000 Our National Health: A plan for action, a plan for change included a commitment to strengthen the influence of patients and public

**2001 Patient Focus and Public Involvement—
guidance to better involve users and citizens**

**2003 Mental Health (Care & Treatment) (Scotland)
Act 2003 strengthens the rights of people with a
“mental disorder” and establishes a right to
independent advocacy**

Adapted from “User and Public Involvement in Health Services
Partners in Change 2002.

The result of these changes is that people now expect to be involved in decisions which affect their lives: they are more likely to ask questions and challenge decisions and are able to access procedures, support groups, forums and independent advocacy services to help them do this.

Benefits of involvement

It is now widely accepted that the increased focus on user involvement has benefits for both the individuals who use services and for the commissioners and providers of those services themselves.

Individuals who feel involved in decisions are often more likely to:

- *Remain well*
- *Recover better from illness*
- *Access care and support from a wider range of people and services*
- *Be less dependent and more self-reliant*
- *Feel more in control and more confident*

Services which involve users in planning, designing, and

monitoring are often more likely to:

- *Respond better to people's needs*
- *Use staff time and skills more effectively*
- *Introduce new ideas and approaches*
- *Use service users experience and skills to help others*
- *Get more encouragement and support from service users*
- *Tap into the enthusiasm and energy of their users and get things done*
- *Make better decisions based on the views and ideas of more people*
- *Make decisions which are more transparent and therefore more acceptable*
- *Win the trust of their users*

Methods of involvement

There are many different ways of involving people both as individuals and groups.

“Involvement” is, or should be, something that occurs in every facet of health care and in every encounter between user and health care services...

...the most significant forms of involvement are those that become part of the day-to-day practice of health care delivery and planning, whether at the level of the individual encounter or at a more collective level...”

User and Public Involvement in Health Services
Partners in Change, 2002.

Some involvement activity can be loosely described as “research” because it has been based on the methods employed by academic and market researchers. Broadly, these methods can be categorised as either “qualitative” or “quantitative”.

Qualitative methods of research offer the best way of exploring peoples feelings, perceptions, and attitudes towards services. The outcomes of qualitative research presents planners, managers and commissioners with the opportunity to make adjustments based on experiences, ideas and themes which may not have been previously identified. Methods of qualitative research include focus groups, user panels, study circles and citizen’s juries.

Quantitative methods of research are more concerned with measuring numbers and incidence—how many and what proportion. Research can be planned so that it is statistically representative and results can be analysed. Questioning is much more structured and is based on current knowledge and the outcomes of quantitative research reflects this. The most common methods of quantitative research are based on surveys of one kind or another.

Independent Advocacy

It is worth noting at this point that many people who use mental health services (and other health and community care services) are not accustomed to being asked their views or opinions and may find it difficult to be involved or consulted. Sometimes this can be because of communication difficulties or simply a lack of confidence. Independent advocacy offers an effective method of empowering people and providing the support they need to be meaningfully involved in decisions which affect their lives. Lomond & Argyll Advocacy Service operates throughout West Dunbartonshire and Argyll & Bute. Details of how to contact the service appear on page two of this report.



PART TWO:

The Project

Project Outline

In partnership with Dumbarton & District Mental Health Forum, and other stakeholders, Lomond & Argyll Advocacy Service drew together an outline proposal combining self and peer advocacy training and a user-led research project into the experiences of people who have used mental health services in the Lomond locality.

Aims & Objectives

The project aimed to recruit and train a small group of people who had experience of using mental health services locally. Having completed training in advocacy and research skills, the objective was that participants would then conduct a number of semi-structured interviews with other mental health service users and produce a report on their findings.

It was anticipated that interviews would be conducted over two days during which support and advice would be available from facilitators. Participants and interviewees would both receive a small allowance to cover any expenses incurred as a consequence of their participation.

The interviews with service users would focus on peoples individual "stories" and their experiences, positive and negative, of mental health services in the Lomond area. Information would then be collated in a report, which would highlight individual experiences and common themes emerging from the interviews.

Support would be available from facilitators to draw together information from the interviews and de-brief interviewers. Participants would then be involved in the production of the report on the background to and outcomes of the project.

This proposal was submitted to NHS Argyll & Clyde who were able to provide the financial resources necessary to finance the proposal.

Once support in principle has been gained from all stakeholders work began to draw together the necessary training materials to equip service user participants to undertake the work identified in the

proposal. Training was designed to meet the following purposes:

Firstly, to assist participants to acquire or develop an understanding of the purpose and value of independent self, peer and collective advocacy by equipping them with the necessary knowledge, skills and understanding to:

- Demonstrate a clear understanding of the purpose of self, peer and collective advocacy
- Be able to define the role of a peer advocate and to identify the skills and knowledge necessary to fulfil this role
- Have the opportunity to develop and practice the skills involved in the role of a self and peer advocate
- Recognise their own limitations and times when it may be appropriate to seek support or refer an advocacy partner to another service or agency

Secondly, to assist participants to acquire or develop an understanding of the role and value of user-led research by equipping them with the necessary knowledge, skills and understanding to:

- Demonstrate a clear understanding of what research is and isn't
- Recognise the advantages and limitations of user led research
- Contribute to the development and planning of the proposed user-led research project
- Have an opportunity to develop and practise the skills involved in conducting user-led interviews and research

A summary of the training undertaken by participants is attached as *appendix one*.

The proposal contained two separate but complementary components: advocacy and user-led research.

Advocacy

Advocacy can benefit any person or group of people who, for what ever reason, find it difficult to put their own case to service providers or do not feel in a strong position to exercise or defend their rights. It is particularly helpful to people who are at risk of being ignored or mistreated, or would like to see a change in the way in which their care needs are met, or are facing a period of crisis or ill health.

Advocacy is increasingly recognised as a valuable way of supporting community care service users and others at risk of exclusion, or people who simply feel confused and overwhelmed by institutions and care systems. It can be difficult for service users to speak up for themselves and advocacy can give them a route by which this may be achieved.

“Advocacy is recognised as a crucial element in providing people with independent information, support and encouragement, to enable them to make informed choices about their care and to remain in control of their own lives. Advocates will speak up for service users and their carers, and will encourage service users and carers to speak up for themselves. Partners will support the development of such advocacy services across the Board Area. Different services are being developed across Argyll and Clyde according to local need. However it is agreed that they should include provision of a service to those currently living in their own homes in the community, to those who may be returning from a long stay in hospital, and to hospital inpatients.”

From: “Our Mental Health And Wellbeing”
A review of the Joint Mental Health Strategy for Argyll & Clyde, July 2002

Types of advocacy

At present, there are several types of individual advocacy available in different parts of Scotland. They are complimentary in nature and each of them may be appropriate at different times. Lomond and Argyll Advocacy Service provides access to issue based professional and volunteer independent advocacy in the Lomond area. There are also other models of advocacy which can be effective in supporting the empowerment of people, including those who use mental health services which are less well developed in the Lomond locality. These include:

Peer Advocacy

Peer advocacy is when a person advocates for another person experiencing similar difficulties. One of the advantages of this type of advocacy is that the advocate has first-hand experience and knowledge of the service users situation, but is not personally affected by it.

Collective Advocacy

Collective advocacy may be defined as a group of service users, working together to promote their joint views with service providers and others. User empowerment is a growing force, not only in mental health services, but throughout the NHS and elsewhere.

As with individual advocacy, collective advocacy comes in a variety of forms. Patient's Councils are a form of collective advocacy, which work in hospitals to present the views of patients to service managers. There are also a number of groups which have been set up and are run by users themselves which have a collective advocacy function, such as local Mental Health Forums.

User-led Research

Investigating users/patients experiences and perceptions is an essential part of understanding what is actually happening as opposed to what we think or hope is happening. Without this understanding any changes to current practices are likely to be dominated by individual

professionals or organisations own views about what good health and social care should look like.

User-led research offers a way of examining services from a user perspective. In Scotland variations on this model have been used in Dumfries and Galloway and more recently in Glasgow. The model relies on service users who are recruited, trained and supported to undertake semi-structured interviews and/or site visits to research users experiences and views on current service provision. Experience outside Argyll & Clyde suggests that this is a highly effective way of capturing service user views in order to inform decisions about the development and improvement of services.

User-led Research can:

- complement other aspects of ongoing mental health needs assessment
- provide a means of going beyond simply asking people how satisfied or dissatisfied they are with existing services and what improvements they would like to see. Information is gathered which can lead to a more in-depth understanding of the extent to which users feel their needs are being met by current arrangements.
- go some way towards fulfilling statutory obligations on the NHS to involve users in the process of developing services to meet their needs by offering meaningful involvement as opposed to token or "tick-box" involvement.

Additional benefits of user-led research:

- Service users offer a cost effective way of reaching the most vulnerable. They can elicit valid, coherent views from the most excluded users of services with the most complex needs.
- Service users are more likely to be told what users really think about their situation than "professional researchers" because of a natural empathy and ability to establish a rapport with the interviewee.

Therapeutic benefits (self-esteem, confidence etc.) are often achieved for user participants

The participation by service users in advocacy and research also offers the potential within Lomond to strengthen the work of partner agencies including Lomond & Argyll Advocacy Service and Dumbarton District Mental Health Forum. It is hoped that the project will also produce lasting benefits in the form of trained peer advocates, collective advocacy groups and a valuable resource which could be employed in future user led research and monitoring activities.



PART THREE:

The Findings

Experts by Experience

As part of the user-led research project twenty-one people who use or have used mental health services in the Lomond area were interviewed by two volunteers from the "Mental Health: What's the Story? Project". The volunteers who conducted the interviews have, themselves, experience of using mental health services. Volunteers first interviewed each other with a further seventeen interviews being conducted over two consecutive days in Dumbarton. Those who participated in the project volunteered to do so in response to a leaflet which was circulated throughout NHS and community facilities locally. Although those who took part do not represent any kind of scientifically based sample they did include a broad cross section of age, gender and background. All participants received a small allowance to cover any out of pocket expenses and support with transport to and from the venue where interviews were conducted.

Interviews were kept as informal and relaxed as possible and lasted no longer than one hour. Facilitators from the Advocacy Service and the social work mental health team were on hand throughout the interviews. Most of the people who participated agreed that the interviews could be tape recorded and then transcribed. All participants were assured of anonymity.

During the first part of the interview participants were invited to "tell their story" and describe their journey through the mental health system. The stories which follow are based on extracts from the transcripts of the interviews which were conducted. Names and some personal details have been omitted in order to protect the anonymity of participants. The stories are always interesting and informative, often intimate and inspiring, sometimes humorous and sometimes harrowing. The people who shared their stories are all experts by experience.



I first went into hospital when I was sixteen, I had an abused childhood. I was raped when I was sixteen and I thought that I was pregnant. I kept hearing voices in my head but I never told anybody what had happened to me. I thought everyone was against me. I ended up taking a massive overdose of my mums' heart tablets and was taken to hospital to see a psychiatrist. I was taken from school to the hospital. I never went back to school again. I was taken to the Argyll and Bute Hospital, Succoth ward, which was an open ward. I started hearing voices again and I was put on antidepressants and was on suicide watch. I kept smashing windows. We used to get visits from the Salvation Army band but when they left I used to start to smash the windows again. I thought the devil was inside me. I hurt another patient and was transferred to the State Hospital at Carstairs. I was there from the age of sixteen until I was twenty-six. I didn't know what life was all about, I didn't have a boyfriend or know anything about relationships. I was a very immature 26 year old.

I saw a resettlement officer to try to get back into work, they decided that I wasn't fit for work; they kept taking my forms out of the returning to work courses. I couldn't understand why they did that because I was trying to get back to work. I eventually got a supported job in the Highways Department of Edinburgh Council. Then I got a job with a mental health voluntary organisation. They made me take a leave of absence because I'd only been there three months when I had to go into hospital again. I took a year out and then went back, but I lost my pension rights because of my lack of continuity of service. I ended up in a different job with a different job description in a different area all together. Then I got made redundant.

After that I got a job with an organisation that dealt with people with physical disabilities, as a training officer for six months, but I ended up back in hospital. I've been in and out of hospital ever since. I was in Edinburgh for about seventeen years, then I came back to Dumbarton where my roots are. I look after my mum now who's over ninety and blind. I've had more support here than I had in Edinburgh. Although I was involved in a lot more groups in Edinburgh and the GPs were more sympathetic there. I did have a CPN too, but because they had to cover a large area I only saw them once a month.

Since coming back here to look after my mum it's become more difficult to stay out of hospital because of the stress of looking after her, even though mum supports me too and helps me pay bills when I'm in hospital.

I've found that services on this side of the country are far superior to those in Edinburgh. I go to the Clyde Unit; I get a lot from the Clyde Unit. I get upset if I can't go. The staff there are great as they are in Christie and ICU (Intensive Care Unit). I thought when I first went back to ICU that would be it for me. I thought that I would be sent back to the State Hospital. I'm scared in the ICU because its only one step away from it especially when I'm on section.



I've always been ill it's been handed down in my family, I'm predisposed to upset. I dislike myself very much. I started off feeling unhealthy things about myself it just churns away inside me, it's like a soundtrack that just keeps going on and on.

My first crisis point came when I was 23 years old when I had to stop working. I had a great doctor, I was changing GP at the time but he treated me superbly, he got me into the system. He referred me to a psychologist but I didn't feel comfortable, I would tell them things and I felt that I was getting a slap on the wrist when they would say "Why didn't you tell us this before?". I just did not find that helpful.

After seeing the psychologist I was transferred to a Consultant who I have been seeing ever since. I think she is super and she is so supportive. I go to the Clyde Unit as well which is super, the staff there are great. There is no-one there that I don't like.

I have had one really bad experience when a friend of mine told me that she was going to kill someone. All weekend I had to calm this girl down until she could see her doctor and this was a bank holiday so we had to wait until the Tuesday morning. At that point I desperately needed a 24 hour help line, just someone to talk to. My friend saw her doctor on the Tuesday morning and had someone to talk to during the week but on the Friday night off she went again. I managed to get her to see an on call GP but she sent her home again and I was left to get on with it.

The first time I really realised there was something wrong with me was when they put me on anti-psychotic drugs, I'm not psychotic but it does seem to have a beneficial effect on my bi-polar disorder. It has provided an interface between me and my disorder. I'm very negative on myself, I still think back to things that happened in primary school and think Oh! No!



My parents died in 1984 but I had my wife then and she helped me through it. Then in 1987 my wife died, I would have went with her if it wasn't for my six year old son, it was very, very hard. I was trying to be a father and a mother, everything to him.

It was actually 1995 before I went to the Clyde Unit. It was the only place that I found comfort. The attitude of the people there was great. If somebody was in trouble a member of the staff was always available to help them. I go three times a week now but the rest of the time I'm in the house. I go to bed at 6.30 pm, my only hobby was swimming and life saving, I used to be an instructor in both, but I found that if I couldn't show people what to do it wasn't worth going at all.

Recently I was in Christie Ward, I took an overdose. I think someone at the Clyde Unit realised something was wrong and they helped me through it. They got me into Christie; I was in for about eight weeks. People don't understand what mental illness is; if you've got a broken leg people can see it but if its something in your head people can't see it and don't understand.

I put on a face all the time. I'm not too keen on talking to people outside unless I sort of bump into them, I try to keep out of their road. I try to laugh and joke about things - that's what I do in the Clyde Unit. I don't know what I'd do without the Clyde Unit. I've met people there, it's helped me through my illness a lot but I just can't turn the corner. I think of my wife all the time when I'm in the house with just the four walls, I look forward to going to the Clyde Unit. On a Monday we have a music group, we take in different kinds of music. Sometimes it makes you feel good, sometimes it makes you feel sad. It just depends on the music. On another day there's a men's group. We can talk about things

that you can't talk about to people outside, they wouldn't understand. Everybody up there has been through the same problems.

If I'm on a high I sometimes get up and walk out but they're very understanding. You can get a meal there; I'm not much of an eater, now and again I'll eat at the Clyde Unit. The rest of the time I just take a jam sandwich, I know it's not good for me but I just don't have a hunger or an appetite. I can't ever remember anything being stolen, the ladies can leave their bags in one room, go to the other room to have lunch, and nothing gets touched. I think that says something about trust.



I know now that I have been ill since I was a child, people used to call me a melancholic child.

I first became unwell when my fiancé took ill with cancer when I was 22 years old. I had to take time off my work with stress; this was after I had done his biopsy as I was a laboratory technician in the hospital at the time.

I went back to work and for several years managed to cope until my mother died of breast cancer at the age of 63. When she died I was off of work for a couple of months suffering from bereavement, and anxiety problems. I went back to work but in the meantime my father took ill with emphysema and osteoporosis and he died a very painful death at the age of 62. I was off of work again for about two months with bereavement and anxiety. Then about two years later my elder brother who was an alcoholic took ill and died a very agonising death after I had nursed him as well. My fiancé was also drinking heavily at this point and I developed a hatred of alcohol. I ended up off work for almost a year then I was paid off due to ill health, which made me feel like a complete failure.

I was referred to a psychiatrist who told me to pull myself together and stop being so bad tempered as I had told him about the uncontrollably violent episodes that I was having. I really am not a violent person as I grew up in an abusive household where alcohol was a major contributing factor, so I tended to shy away from violence of any sort

normally. This made me feel as if I was some sort of evil demon and I don't know how my fiancé put up with me.

I was referred to the Clyde Unit by my GP I thought I was going for bereavement counselling. When I went for my interview I felt like I was being interrogated, then they asked me to wait outside till they made up their mind if I would be accepted or not. I was, and I attended the day of groups for several months. I thought I was there under false pretences but gradually things started to come back to me in flashbacks, things that had happened to me as a child that I had blotted out.

I went to an anxiety management group which at the time I thought was useless but I soon discovered it was helping me to cope with my panic attacks. I couldn't leave the house myself until then. I also went to an assertiveness group which made me realise that I had rights too, until then I had been everyone's doormat. I went to an art therapy group for about eighteen months this was very good and let me talk about things that were worrying me.

I had a CPN who was wonderful. She got me referred to a psychologist who I think is a fantastic person. She got me to face up to my problems which included my obsessive compulsive disorder, which was controlling my life. The work with the psychologist was very hard but it was worth it in the end as I can now do things that I was unable to do before.

When I was at the art therapy my CPN had suggested I get cognitive behavioural therapy but the occupational therapist at the art therapy group said I didn't need it. I feel that if I had got this when my CPN had suggested it would have saved me several years of being stuck in the house afraid of life. What gave her the right to decide it wasn't for me? In the end she was proved wrong and it helped me tremendously. When I was discharged from the art therapy group I was left with nothing and I was very scared. I was asked by my CPN if I would be interested in a ladies exercise group that was to start in the Concorde CE centre but this only lasted a couple of months. I had hoped it would go on to be like "Activate" the men's group but it wasn't to be. I enjoyed the exercise group very much.

I then saw another psychiatrist who put me on many different sorts of anti-depressants but nothing seemed to work. I was spending

thousands of pounds on goods that I didn't need and clothes that I never wore. I was told I was suffering from clinical depression at that time. Then my psychiatrist left and I saw another who was a great help to me. It was that psychiatrist and my CPN who decided that I should have the cognitive behavioural therapy. Thank goodness!

My CPN left to go to another job and I was left without a CPN but I was asked if I would like to see an occupational therapist - not the one who said I didn't need CBT! - who I agreed to see. It was whilst seeing her that I admitted some of the things that had happened to me as a child. She has helped me work through some of them but I find it very difficult and can't deal with it all at the moment.

When my psychiatrist left I was very distressed even though I understood why she had done so. I went to the user and carers meeting at the hospital with my husband and decided to get more involved with the Mental Health Forum. I went to the forum one day and was voted onto the committee and have been there for three years now. I am a member of a group set up to discuss service planning but I feel we are there in name only. I don't feel that we have any real say in the matter.

In July 2003 I lost my other brother to alcohol, I only have my husband now and I was feeling really low. I had a crisis and was feeling very suicidal I didn't want to tell anyone but I had an appointment with the occupational therapist and it just came out. She took me straight down to see my GP, who sent me up to Christie Ward, I saw a duty SHO who asked me about my story, said she couldn't do anything as I was to see the consultant next week and she sent me home. If it hadn't been for my O.T. I might have not been here today, as for the SHO she was a waste of space!

In the last year I have been found to have developed a lot of allergies and intolerances so I am finding it difficult to get a medication that works for me at the moment and we are still trying to find a suitable one.



I was first ill after my little boy was born, he's now fifteen years old. I was diagnosed with post natal depression but I went a long time before I went to see my GP to say that I was having problems. I went back at different times and tried different things but finished up being taken into Gartnavel Royal Hospital and I feel it was just the worst experience ever, I was so frightened. I don't think I should have been in there. There were people who were seriously ill and I had never seen anyone with a mental illness before and I was really, really scared.

My husband was just left to look after the children a toddler and a baby with no help. It was a case of I was just taken into hospital and he also had to go to work as well as look after the children. We had no family in the area and I felt that he got no assistance to look after the children. Nobody said who's looking after those two children?

Then I came out and for quite a number of years just went between well periods and periods of illness. In 1997 my GP said that he thought that I had a deeper mental illness, and that it wasn't just post natal depression. He thought that I was having highs and lows and he decided that he wanted a second opinion. He sent my notes away to a psychiatrist and between my notes and the fact that I was having hallucination and things like that they decided that I was a manic depressive.

Then things changed, I was taken off of antidepressants and put onto Lithium. I became very ill and the psychiatrist referred me to a CPN and I was hospitalised in the Christie Ward. At the same time as I was going through this my daughter became ill and took a massive overdose, she was just fourteen years old and I felt that I was trying to look after her as well as look after myself at the same time. So I've seen things from the point of a service user and also the point of a carer.

In relation to my daughter I was appalled with her care, I took her to see a GP and she was there three times in regards to problems she was having due to menstruation and it was fobbed off as due to her age. It turned out after a year that it was due to a hormone imbalance and that was the cause of her going into this really bad depression. It was a chemical imbalance and if they'd done tests a year before she would have been saved all this. She ended up in hospital for nine months in

the Adolescent Unit at Gartnavel. The whole environment up there was awful I mean you don't expect beautiful surroundings but it was so drab and so miserable looking and these were all young people in there. The doctors and nurses were very good but what she found very hard was the constant changing of nurses. She was there nine months and she had a key nurse for maybe three months and then they would change, she would have a good relationship built up and then they transferred somewhere else and she had to get to know someone all over again. Or maybe there would be a nurse on and their speciality would be say anorexia and they would have no idea what she was going through. The facilities were very poor there were no funds so there was no money to get simple things like videos at the weekends, small things like taking them out on trips, the ones well enough to go that is, like to the pictures. They'd end up using the budget in the first week. That was to help her socialise so that when she got home on a weekend she didn't want to socialise. She wanted to be back in an institution she felt that was where she belonged so that was a problem

As soon as she was sixteen we, as parents, were not given any information about her condition and that was awful as to me she was still our child, one day she was a 15 year old and the next she was 16 and that was it, you didn't get any more information. You felt really cut off.

During my stay in Christie Ward some of the nurses were very good but that phase when the psychiatrists resigned was going on then. I had a Consultant and at that time I was really unwell and there were a lot of things that I had confided in the Consultant about in relation to my childhood, personal things. All of a sudden they were away, gone. I was given another psychiatrist but I never went back to talking about things again, I've been through it all before and I can't do it again.

Now my CPN says that he has to lose some of his cases and he said that he will try to hang on to me because I have had quite a few issues to deal with in the past year. I know that you can't always see the same person but it seems to me that they can't keep their staff. There must be something wrong if they can't maintain a certain level.

When I was in Christie Ward you knew that you were in hospital: the surroundings were very basic. While I was in the TV in the non-smoking dayroom was broken and I couldn't go into the smoking room because

I've got asthma. If I wanted to see the news, there were maybe ten or fifteen people smoking, so I just couldn't go in. When I asked why can't we have a TV in the non-smoking room it just fell on deaf ears. At this point I had been in for six weeks and the telly was broken all that time.

One thing that I really enjoyed was the occupational therapist's visits, she would come and make cakes for instance and it took your mind off things even if your head was racing and your stomach was doing somersaults. I think that there wasn't enough of that sort of thing, she only came about once a fortnight. I think you need something each day, even if it's only for an hour, to focus on. Mostly it was just sitting on your bed or going to the smoke room to watch TV, which I couldn't do so I didn't get much therapy. To me the only benefit about hospital was to get a break from looking after the kids, some space and time. I feel that there was no rehabilitation. I was put on an awful lot of medication when I was in hospital; maybe the doctors thought that I needed it. When I went in I was on my basic medication when I came out I was on nine different drugs. I was getting side effects so they gave you a tablet to stop this then they would give you something else to counteract the side effects of that one. My GP was absolutely horrified when he saw all the medication that I was taking and he very slowly weaned me off of them. Since then maybe now and again one is added, maybe diazepam or something to help me sleep. Now my medicine is kind of stabilized. I've seen it sometimes that I don't take my medication so if I don't order a prescription. Surely someone should pick this up. Wee things like that make you feel that you could slip through the net. If I miss a GP appointment no one checks up on me, but my GP is very good if I have to sit and talk to him for 30 minutes he will let me. If I get worried about the time he says that he invited me so don't worry about the time. If I miss it, it is because I am unwell, how do they follow up on this. I was on holiday and we were delayed getting back and my CPN had left messages asking why I hadn't been in touch with him and if I was OK. So he keeps tabs on me. He also helps me with practical things; he'll help me make a list of things. Maybe if the house is in a mess he will help me make a list of what needs done today and what I should leave until tomorrow. People who don't have a mental illness don't realise that you sometimes can't think for yourself, you can't sit down and say I need to do the hovering etc. you can't put it together. He helps me plan things to do with my housework. Talking is good but there are times when practical advice is needed. When the kids were small and I was really ill, if someone had come in and said

you need to do this and that it would have helped a lot. You don't want them to do it for you just to help you plan it.

From my husbands point, I don't feel that he was given enough information and maybe some material for the kids to understand would have helped. Somebody to explain why mummy was doing these things, my husband had enough trouble understanding it himself he couldn't put it into words for the kids.



The first time I had a problem was when I was diagnosed with cancer in 1984, I was just 22 yrs old. I was having problems dealing with things and I was referred to see a psychologist at Gartnavel by my oncologist. The psychologist told me to think myself luck as there were children upstairs dying in the wards. This did not alleviate my fears it just made me feel guilty, so I never mentioned it again. I tried to plod on myself and I started to drink alcohol to blot out my worries, which it didn't.

I was working at the time and found that when any changes were made to my job or I was given more responsibilities I ended up being off work due to stress. Small things made me panic all the time. This happened several times but I only saw my GP for this problem, she was very supportive but I wasn't given any medication or anything like that.

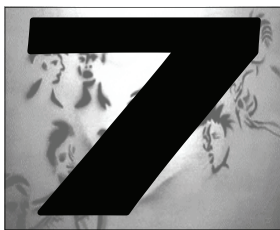
I was still drinking during this time but found myself hiding it from my family, I didn't like to talk about my problems. I had several health scares as well, being recalled to the oncology clinic and also being diagnosed with another life threatening condition. It was a very stressful time for me and my family.

During this time my wife lost her mother to breast cancer, then her father died and also her elder brother. We were both finding life a struggle and she has since been diagnosed with bi-polar depression which is very hard to cope with, she can be very difficult to live with and has since lost her job.

In November 1998 my mother was finally diagnosed with cancer after

several months of misdiagnoses. I found it extremely difficult to cope with and my drinking increased. After watching this and my mothers death I became too ill to work and was put on the sick by my GP, who was a great support to me. I was referred to see a psychiatrist but unfortunately I couldn't develop an understanding and had difficulty communicating with each other. I found this very upsetting and frustrating as I was very ill at the time. My wife spoke to someone and I was referred to another doctor who I built up a great relationship with. I felt I could trust her. I find it difficult talking to people and she made this easier for me. I was also referred to a psychologist but did not find this helpful as I felt uncomfortable with her. I did not like going to the Joint Hospital because of the stigma involved with it either.

When my doctor resigned in protest to the lack of funding I was very distressed. I see a locum but do not feel very confident with him. He may be overstretched, I don't know, but I was shocked when at one appointment he told me to go out with my wife for a drink and relax. At this point I had stopped drinking for about two and a half years and my wife had just lost her second brother to alcoholic liver disease. Did he not read my notes or listen to me.



I first got referred from the doctor five years ago. The thing that was wrong with me was I was really depressed and wasn't doing anything, just sitting in the house. I was going out occasionally but I was out drinking. I was doing things that I shouldn't have been doing. I thought that was helping my depression but it was actually making it worse. I went to the doctor and he referred me to a CPN who introduced me to the Activate club, I've been going for the past five years and it's really good.

The first two years were a struggle but I was slowly getting there but sometimes I fell away from it but then I would go back. I also joined a drop in club on Tuesday mornings just to meet up with people and to get into company. I had low esteem and had lost hope. It gets me out of the house meeting folk and going places with them. The staff there are very good; if you've got any problems at all you can speak to them

about it. I've also joined a running club and have run in a couple of races. I went to college last year which I wouldn't have done before. I was on a catering course and I passed my five modules. I enjoyed it so much that I'm going back this year to do the same sort of course. I would say this year has been the best in the last five years; I've found a level I'm comfortable with.

Part of my problem is that I've got dyslexia so I've got problems with reading and writing, but I'm getting that sorted out. I'm going to classes at a community centre. That's what the main thing is for me. To get that done. I find it all really difficult to cope with.

The first three years were difficult, the last two I'm starting to get a level now. I am also in contact with SAMH.



I'm still seeing psychiatrists at the moment. I've had I social workers, a CPN and a psychologist. I found the psychologist very helpful.

I was abused when I was younger, between the age of five and fourteen. I left home at sixteen as I could not handle being abused any longer. I hit the drink and was an alcoholic for fourteen years.

I have three children, but my husband abused me too, mentally, physically and sexually. I left the marital home and got help at the women's refuge. I lived alone for ten years. I felt very isolated. I didn't want to speak to anybody. I stayed on my own and just didn't want to face anyone. I felt I was on my own nobody could harm me anymore. I felt the only way I could survive was to stay on my own. Having said that I didn't like being on my own. I hated my own company, you don't realise how bad you are within yourself, being depressed and isolated, you can't think straight. You don't know what your good and your bad points are. There's nobody there to say, wait a minute you're a wee bit depressed or you need help. I didn't have anything like that.

My condition got worse over the years, then in 1998 I tried to commit suicide, I felt I was at rock bottom. I felt there was no point in living anymore, I felt that was my time, I don't belong here and that was it, so I tried to commit suicide.

I was admitted to the Christie Ward that's where I was introduced to SAMH the best thing that ever happened to me: all the support I've had and the encouragement. I'm now going to college one day a week, to do my English. I've also been doing voluntary work.

I'm hoping within the next two years that I will be healthy enough and well enough to hold down a job whether part-time or full-time. My aim is to get myself back in to society and a working environment again. If possible I would like to work with people with mental health problems. I think working in that kind of environment; if you've had problems yourself you know what it's like. I would like to pass on what I have learned through SAMH and my CPN. Also attending the Acumen meetings, it makes me realise having a mental health problem isn't the end of your life. Basically to me getting over a mental health problem and getting back into society is a huge step to take, but I feel I could help someone else by giving them a bit of advice. To me life can be better; it takes a lot of hard work to get yourself back on the straight and narrow and making a life for myself. It's been a hard struggle because I've not had any support from my family, when they found out I had mental health problems they didn't want to know. I think it was because they didn't know how to deal with it. Their attitude was you don't stay with us we don't have to see it. It does affect the rest of your family and everyone else around you. I'm now in a position I am a user of groups for people with mental health problems, SAMH, the Wednesday morning group and the women's group. I've had a lot of support from that and I feel I have put a lot back into it, because I do get involved in the groups, that is my way of putting something back.

My life is changing now; my son and daughter are back in my life. They were not in my life for a period of seven years. We are close now, really close. They are no longer turning their back on me; it's good that I've got them there. If I didn't have them I would only have my partner she suffers from mental health problems as well so it's not easy.

Things are looking good at the moment hopefully it will continue that way.



I first had my breakdown when I was 21 years old, over forty years ago. It started with bereavement and in the meantime I joined the army but I couldn't make a go of it and bought myself out. The bereavement came just after that, my father died. I had a job but got paid off and the next thing I started drinking a lot for about three weeks solid. I went to Dundee to see my uncle and I got picked up in Edinburgh by the police. I didn't do any damage to anybody or anything like that. I finished up in a Dundee mental hospital. After that I got quite a lot of ECT. They sent me back to Gartnavel and I was more or less cured. I wasn't even on any medication or anything. I went out to work again, I worked locally and then me and my pal went down to London. We got jobs in Birmingham then we came back up the road again. Then I met my wife, my mate went somewhere else and everything was moving along. I was working in different jobs most semi-skilled jobs. I joined the T.A. but things went wrong while I was away at the camp, it was a pretty noisy camp, and I just began to lose my grip on reality. I couldn't settle in my job, which was in a whisky bond where I could get drink for nothing and I hammered that as well. So at the finish up I was back in Gartnavel. Since then I've been in and out of hospital for quite a while. My wife had an awful time with me but she stood by me through thick and thin.

A community worker suggested I come up to the Clyde Unit and I started attending every so often. I was on medication but they were worried about side-effects and changed them. Of course I went as high as a kite so I had to go into Christie Ward. My wife was as faithful as ever, I didn't think she would come back to a psychiatric hospital again. She came and brought me things to eat, tobacco and money, that was about three years ago. I've been attending the Clyde Unit ever since.

I've had a few jobs but I've walked off two just because I could hear voices and that. I used to be up at night a lot too, I used to call it the long night watch. I would be up while my wife and kids would be sleeping and I would be thinking, thinking, thinking.

I would set the alarm for 7.30 am and I was in bed all night awake. So before the alarm went off I used to press the button but I couldn't lie back and go to sleep. This went on all week. I didn't have any medication so on the Friday night I went up and got a bottle of cheap sherry poured myself a couple of glasses just went to bed and slept.

I've not joined the AA or anything but I've been sober for fourteen years. I don't drink at parties, New Year or birthdays. My daughter takes an occasional drink, my wife likes a can of lager. We help each other; we've been through the mill together. I've got my own house now but we work everything together. Life changes, but now I've got a better life. My kids are grown up and away now, I lost a daughter: she was only thirty-four when she died. I've said to my wife: " You know we're having not a bad time now". Stopping alcohol has an awful lot to do with that. I read an awful lot of books. I read the power of positive thinking it was very good. I've got a television now, my wife bought it for me when I came out of Christie and I've always kept a diary, I've got diaries everywhere. I do a bit of sketching and now I've got the clarinet back in my life, I play with my son-in-law on a Saturday night, he plays the guitar.



It started when I was 11 years old, two weeks after my eleventh birthday my mother died. I self harmed and started to take my dad's tablets. I started drinking and taking loads and loads of tablets. They made me see a psychiatrist. The psychiatrist asked me why I was hurting myself. I was being abused, incest, but I didn't tell anyone what was going on, nobody knew. They classed me as a schizophrenic. I wanted to have weans and a decent life, but I was still taking drugs and cutting myself and things went down the slope again. My dad went away to see my sister, who was now married and I was sleeping in my dad's bed till he came back, a sofa bed in the living room. One of his pals came in and he tried to get into bed with me and he put his hand over my face. I sat up for two nights waiting for my dad to come back. I told him what had happened and he just said "Oh, Well.". I hated it when my dad's pals would paw me. It was horrible. When I told my family about the abuse they all fell out with me.

I was drinking, taking drugs, cutting my arms, my breasts and legs and still taking tablets at this time. I was in hospital with numerous overdoses, twelve times, and cutting myself. I went to see a psychiatrist, I felt dirty, filthy.

I was referred to a CPN, by my GP, I think. She used to come and see how I was doing and if I was needing a helping hand with things. Just talking about things that was the start for me. Then I was referred to the Clyde Unit which I thought was a day centre. When I first went the staff were all sitting around a table. I told them what had happened and then they asked me to go out so that they could discuss my case and whether or not they would accept me, they did. . I thought I was going for one day, for a talk and a cup of coffee, that one day turned into fifteen years!

I went to America for a six week holiday but I had to come back after only three because I took ill. I had my medicine with me, injections, but I didn't know who to go to to give me it. I couldn't find a doctor so I took ill and had to come home. I was put into Christie Ward and seen by a social worker who referred me to the Richmond Fellowship and they've been great the only people who have helped me. I'd just slipped through the system.

I like people, a wee lassie was staying with me for a while but I found her stealing money out of my cardigan pocket in my bedroom one day. I told her to put it back and get out. That hurt me. I had a friend too; we were together for about four years before he died.

I went to one of the Churches in Helensburgh and I was helping out with the children's groups. I saw all the old folk and said to them: "the kids have got plenty of help, I'd like to help the old folk, as they were all just sitting about." I like doing voluntary work it helps me. This is great I feel as if I'm famous!

All in all, The Richmond Fellowship is the best thing that has ever happened to me. I wouldn't be here without them.



When my husband died I was attending my doctor monthly for quite a while. He said that they were trying to get something going with the CPNs for bereavement. One of the CPNs asked me if I'd like a visit from her and I said yes. I felt that I needed

it. The doctor got the CPN to come to the house, at that point I felt my world was finished as far as company with other people and enjoying myself was concerned. I just felt why should I laugh again when the one I want isn't here? My two girls were very good we have a close routine but they still let me do my own thing.

My minister gave me the phone number of a lady who came out to see me once a month and she sat and tried to talk me through it. At the beginning I couldn't talk about my husband, I'd get all choked up. She would make me a cup of tea and she told me that had lost her husband when her children were young, they were now grown up. She visited me for eighteen months or more she made me see that I was progressing, even though I couldn't see it. I still keep in touch with her, at Christmas time and that.

The car we had when my husband died was a wee mini metro; we'd only had it about a year. I asked my youngest daughter if she wanted it but she said no she wanted me to get back into driving. She told me to book some lessons and she would also take me out. It meant that I could go to church, supermarkets and so on myself. The instructor was very good he told me he couldn't teach me anymore. Now I've driven to Aberdeen and I went to Inverness to my husband's cousins, his wife came down on the train and she travelled up with me in the car. So it's through nice people that liked my husband and me that I've managed to get through this. The CPN came about once a fortnight for a while then she told me about this bereavement group that was starting in one of the churches and I thought it would be good to speak to others in the same position as myself. Some people went up to the grave every day but my husband new what I did for him, so I only go up once a week to tidy things up.

I went away on a bus tour a few months ago and it was the loneliest holiday I've ever had. It wasn't until I got home that I broke down about it. A couple befriended me. The man must have noticed on the bus how upset I was and gave me a book to read. I think now the ups are a wee bit more than the downs.

I keep in contact with my two daughters and their husbands and kids.

The bereavement group helped me; they were great and they helped a lot. There was a wee lady who was very upset she had just lost her

husband and I thought Oh! Was I as bad as that at first? I'm lucky I've got my two girls, she had no family. I was looking through a box of things one day when I found a letter from one of my daughters to me and her dad thanking us for the lovely wedding that we had given her. I think we brought them up well to respect others. My husband always sorted things out and I thought I could never cope without him but I am.

I was given tablets for depression and the GP explained it saying it was like being in a hole that you have to climb out of. My own GP is very good, another GP goes to the same church as myself and my husband did and he sent me a letter saying that he was sorry to hear about my loss and that if I ever needed to speak that I was just to come and see him anytime. Someone else gave me a book of thoughts for every day. One of them said something like "The Lord will not test you more than you can handle". Maybe I've not had it so bad, I had my husband from 1953. It's very hard to be without him. I had my Ruby wedding and I'd have loved to have had our golden wedding together. Now I am trying to stand on my own two feet



I first had problems just after puberty, I used to act differently. I can't understand it or explain it, but I acted differently. I acted really immaturely for my age and did really stupid things. I was very down and became very depressed, it all started coming to a head when I started to develop feelings for girls and it got really difficult for me. I didn't know how to handle it. That was also making me feel very depressed, by this time I was about sixteen and the problem was I wouldn't say anything to anyone and it all built up.

My mum and dad thought I really needed help because of my behaviour in the house, after being annoyed at school and being down I took it out on my family. They took me to see an adolescent psychiatrist up at the Vale of Leven and I was put on antidepressants. I can remember my dad saying to me at the time don't tell anyone at school because they are known as the "happy pills" and people will make fun of you. I started taking medication when I was around 16 or 17. The medication

made me feel a wee bit better but I was still getting picked on at school. I was starting to become suicidal, I tried to choke myself with a school tie in the classroom because things get to you, and you start to do silly things. I wanted to jump off the stairs in school, so a few times the guidance teachers had to phone my dad to come and take me home early for my safety and the other pupils' safety.

I still went to school, though my mum and dad wanted me to leave because it was well after my exams and I was going into fifth year, so I could have left but I wouldn't do it. It all came to a head one evening when I just cracked. In between then I still had regular appointments with the psychiatrist. I always dread going to see the psychiatrist because we were always talking about bad things. When I finally cracked up I just couldn't take anymore. I wanted to jump out of my bedroom window. My mum and my sisters were really upset they had to phone my dad to come back home early, he didn't finish work till about 6 O'clock and this was about 4 o'clock. My dad took me to see the Psychiatrist. She was just about to go home so we caught her just in time. I decided to admit myself to Christie Ward because I was feeling suicidal, even though mum and dad didn't want me to go in. I was there for four weeks and I felt I really needed help.

Even though I knew I needed help I didn't help myself. I was expecting the nurses to wave a magic wand. After four weeks I was transferred to Gartnavel Adolescent Unit. There were only ten beds there so I had to wait to get in. I paid a visit to see what it was like and it was ok. I started going to Gartnavel when someone else was discharged. Things just stayed the same, it was difficult in there because it was mostly girls and being a man with feelings it was difficult for me. I made some friends in there, nothing against the Christie Ward but it was a bit more relaxed in Gartnavel. I was in Henderson House, upstairs was like an elderly unit and downstairs was the adolescent unit. After a while I could go home at weekends, which was very difficult for me because I felt safe in hospital. In the place where we lived people picked on me. We went outings to the pictures and the bowling, it was going into the summer and it made it a lot more relaxing. The bad thing about it was I still wouldn't help myself in any way. The nurses would struggle to get me out of bed and I wouldn't get up till 4 or 5 pm and the doctors would be away home by then. I was told by my dad that the reason I was discharged was because I wouldn't help myself.

The diagnosis I got at the end of it, after seeing a speech therapist from Yorkhill, was Asperger's Syndrome, which is a mild form of autism, so I like to stick to routine and have obsessive hobbies. In the end it was quite a relief to find out what was wrong and the reason I acted so differently from other people and what caused me to have depression. I went in to hospital in April and was discharged in August. One of the teachers that came in recommended that I go to Cardonald. I didn't want to go to Clydebank because people I knew from school would be there. The month in between this and going to Cardonald College I felt didn't help me; I was just sitting in the house doing nothing. I went to Cardonald and finished off what I had started in school. That was the start of recovery, that's when I decided to help myself, get into college and get on with life. I also started seeing an occupational therapist. After two years at college I'd made some friends and actually felt relaxed. I achieved a few things, I didn't manage the "Highers" but I felt good.

After college I didn't know what to do so I started getting involved with groups, a writers forum was the first. I also got a new outreach worker from SAMH as well. When I was in college she recommended a few groups. There was one on a Saturday which got me out the house as I was doing nothing anyway; I was bored because college wasn't on. I then joined a drop in group and started to get really involved in groups. A few months later I was asked by someone to go to the Mental Health Forum; I went to see what it was all about and was pretty taken aback by all the business. Without realising it I was voted onto the committee and from then on I got really involved in committee work. This made me get more involved in the community and to help other people and to have responsibilities. I still don't think we have a proper voice. I feel it's just tokenism, that they only let us on panels and things because the Scottish Executive has told them to, but users should be listened to Seriously, not just be bums on seats. Were not taken seriously enough.

Hospitals are not ideal places, there are a lot of ill people there and you don't want to upset anyone, you feel insecure. It was funny in the Christie Ward, I thought because of what society says, that when I went into my room at night I was going to be locked in, but I wasn't. The experiences that I had are not as bad as are portrayed. There are a lot of flaws at present but during my time in both Christie and Gartnavel I found a relaxing atmosphere and the nurses were good.

I'm still in the system, I still see a psychiatrist, a few different ones since the resignations. I'm stable just now and don't think I need to see a psychiatrist unless it's an emergency, which I'm confident I won't need. Even though the system has its flaws I feel the system has done great for me, somewhere you can get help.



I've been unwell from about five years of age, my family didn't know about it, I just withdrew into myself, and I was very quiet. It didn't come to a head until about four years ago. I had gone into my sons' school one day, something was going on for the boys but for some reason I just couldn't go into that assembly hall. The more they tried to get me to move the worse I got. I couldn't remember names or phone numbers. I was just panicking. I'd been to the doctor the week before but I couldn't tell him what was wrong because I didn't know myself. I was acting strangely and I didn't know what was going on. The school finally got my son out of the assembly, the eldest twin. They got my mums phone number from him because I kept telling them it's in the box but they couldn't understand what I meant. I meant in the computer but I couldn't get the words out, it was like words totally vanished. I kept thinking I know the word so why won't it come out of my mouth. They finally got me to my mums' house, everyone was petrified at the school, the kids and my mum were very upset. It was like being frozen, you're there but you're not there. Everybody is asking you questions that you can't answer, they phoned the doctor and my brother came with me. When I finally got in to see her I just shouted "help me!" And she said help you do what? And I said "just help me!" She said you're safe, you're OK! I just said "help me!". That's all I could say for I don't know how long. Then they took me to Christie Ward and kept asking me questions, but no-one could understand me because I was speaking in my strong northern accent and they didn't know what I was saying. They got one of the nurses from the main hospital that came from Aberdeen and even he was finding it difficult to understand me. My head was going at about 1000 mph, but to me everything seemed to be going in slow Motion. I thought they were playing tricks on me.

I don't know if I stayed there that night or not, but they sent me to

Lochgilthead and I hated it. They wouldn't even let me out the door. I said "I'm in a strange place where would I go?, I don't know where I am anyway!" I didn't know when I was going to see my family. There was no car or bus then. My ex husband, the girls dad, brought my mum and my daughter up to see me, but I felt very isolated from my family and friends up there. The other patients in the hospital were very nice we didn't ask each other about our problems just if you wanted to speak about it... But I really loathed that place.

I didn't like the doctors and there were 2 or 3 inches of water lying in the bottom of the shower cubicles. That's not hygienic, but when I complained about it they thought I was joking. It wasn't until one of the staff came into see it and I asked "would you take a shower in here?", they said "no" and I said "then why should we?". They told me nobody else had complained. I said "well, I am!". There were four cubicles and only one of them worked. They were not pleased with me. I was seen as a troublemaker and was told to shut up and keep quiet, not to say anything. I'm a person with rights, why should I?

I had an argument with a doctor. I said "I want home I don't like it here" but they said I couldn't go. I've been really lucky I suppose, that first time that I was in hospital has been the only time Thank God! Touch wood that I never have to go in again. You feel as if you're not a person.

Soon after that I got back to Dumbarton, I just kept complaining if I didn't like something and that didn't go down too well. I kept asking questions all the time. I wanted to know what my illness was. I said "tell me my diagnosis", but they still didn't tell me. I would have felt better if they had told me. I've got dyslexia and if they'd have explained it I would have understood better what was going on. It took me a long time to learn to read but if someone had just explained things to me. One of the nurses was very good he used to answer my questions, so I kept bombarding him with more questions. It was through him that I found out what the drugs was for. I finally got to talk to psychiatrist who was touring hospitals, four or five weeks after my admission. I might have spoke to another but I couldn't remember I was too ill.

I also suffer from a bad back and asked for some painkillers but they said it was all in my head, my medical file should have been with my psychiatric file so I kept begging them to phone Dumbarton Health

Centre to find out about my back.

I finally got a diagnosis from a psychiatric nurse who asked me if I knew what was wrong with me. I thought why didn't they tell me all this two years ago. I said tell me what it means in words that I can understand. She did her best to explain to me, but when I get upset I just can't take things in very well. My eldest daughter got some information from the internet but I think it is wrong that we have to resort to this. The majority of things you just have to find things out for yourself

I've joined a drop in and I've also joined Acumen. I get their newsletter and that is good. Now I get to meet people. I told the psychiatrist in the hospital "look I'm me, I'm not just a number. My personality is mine, it might have been hidden for a while but nobody can take away YOU!" I said I'm frightened. He asked why and I said would you not be frightened if you were taken away and put in a place you don't know, with people you don't know, when you don't know why you're there or if you'll ever see anybody you know again? When they put me in Lochgilphead I thought if I don't help myself who else will help me? I started crawling my way back; I thought I'll get to the end of this thing if it kills me. If I don't get out of here I'll die and I've got four weans and my mum. So every time it got further away I just said you've got to get up again. Everybody has their own personal hell, I called mine a tunnel, some say its like a pit or a fog. I felt like that as well, but at least with a tunnel you can see the light at the end!

Groups like this help, people talking to other people, people that know how you feel. You understand a hell of a lot better than them, going through their books and documents. They only listen for a wee while then they shut off. It also helps if you've got a permanent doctor, it helps because you get to know and trust that person instead of somebody new all the time. You feel as if you can't open up, you think what's the point I'm going to get someone else in two months!

I've just recently been given a CPN, she's excellent. I've been lucky I've had a few big dips but have not hit rock bottom again. You never know what is around the corner though. My sons asked me to promise never to get ill again but I had to say I can't do that, you can't promise anybody that. You could walk out the house and fall and break your leg,

you never asked for it, it just happens.

There should be more education about mental illness. I had a neighbour who called me a "psycho", it hurts really badly when people do this, you don't need people making it worse!

Unless you've been through it or been with someone through it you can't understand. You don't know if you're upside down or back to front. To know that someone understands is great. You wonder why people don't listen, it's because people don't understand. It's like when I was little it wasn't that someone was ill, they were "a head case" or they were "bad with their nerves" – your nerves run from the top of your head to your feet, where do you put the plaster? Sometimes you feel like putting a plaster on your head to stop it exploding!



I started feeling unwell and I didn't know what was wrong with me, I'd never been ill in my life before. I was having these kinds of flutters and I thought that I was having a heart attack. My pal ran me down to the doctors' surgery but by the time I got there it was gone, so I dismissed it. That was the first panic attack. Then I started having them a lot. It happened at about the time my marriage broke down, but that was well finished. They said it was my marriage breakdown that caused me to have a breakdown. I do not agree with that because the marriage was well finished by that time. I lost my job as well, I was good at my job, I was a care assistant and I could get a job anytime, but eventually my brain switched down and then switched off. The GP gave me tablets, no explanation or nothing. I'm dead against tablets but I took them. When I started to feel better I stopped taking them and unknowns to me I should have kept taking them and I had a full-blown panic attack. I didn't know what was happening to me and I sent for the Doctor. She came to see me and said "Lochgilphead!"

They took me to Lochgilphead but they didn't tell me anything. It was a terrible experience. Still I got no explanation, I just kept getting taken into a room with about five people sitting looking at me. I was literally on my hands and knees begging them to help me.

This went on for the whole six weeks I was in there. For two weeks solid I paced up and down the ward and I lost two stone in weight. This upset the staff and I felt they were annoyed at me for walking up and down the ward. One night in particular the staff said "You'll sleep tonight" and I said "Thank God, you're going to give me something to help me sleep tonight". I thought that was fair enough. Another time I was walking up and down the corridors and the staff took me up to the office at the top of the ward. It was the middle of the night and they kept trying to get me to sign a piece of paper. I said that I wouldn't sign it. I later found out it was to discharge myself, so that they could put me out. This happened about eight or nine years ago. It was horrific and I was terrified out of my mind. Nobody could calm me down.

If somebody had just sat me down and explained to me what would happen, but nobody said this is what's wrong and this will happen, this is why you are like this. It was just mumble, mumble, mumble and in and out of these offices. Nobody sat me down and told me what was wrong with me. I told the head doctor when I was leaving what had happened to me. She said "I've taken it on board". I said you take patients in and think that we all know the system but this is my first time in hospital and none of you have explained anything to me. She came to see me the day that I was leaving and she said sorry and she would take on board what I was saying.

I'd never known what illness was before this and I feel that the system let me down in a lot of ways. They just kept giving me more and more medication but I knew this wasn't right and I eventually had to say I wanted off it. I don't like a lot of medication, I asked the psychiatrist if I could get off as many as possible. I have to take some but I've got off of most of the rest. Because of the situation with the psychiatrists you have to keep telling your story, then six months later you have to repeat it to another psychiatrist. I cry all the time when I talk about being in hospital.

The patients are very protective of each other though, they look after one another. You can phone each other for help and they help you through the bad days. You need to talk to someone.

A large, bold black number '15' is centered in the image. The background is a grayscale collage of various human faces, some looking forward and others in profile, creating a textured, layered effect behind the number.

I was 20 years old when I first suffered from nerves, I was on medication which didn't suit me. I came off that and went on something else. Then I met and married my husband. My marriage did not last longer than eight years. I became very nervous and frightened of my husband. I ended up getting more pills from the doctor. I made my way into Dumbarton and stayed with a friend. I got threatening letters from my ex-husband about bank statements and things like that. I was sending him money to pay off debts. The lady I was staying with was my mums friend and she had a bad heart and I couldn't have him coming to the door. I nearly had a nervous breakdown.

I was sent to a clinic in Glasgow and asked many questions, who my parents were, what ages they were. I came back from Glasgow and they wanted me to go to Lochgilphead but I talked them around. I went to the health centre and the doctor gave me pills to take. After that I got a house, the one I'm in just now. I was 30 years old at the time and was working then. My ex-husband found out where I lived and I ended back on the sick through nerves. I had police protection right enough.

Then I had my son and I got postnatal depression and went into Lochgilphead. I took my son in with me and they put me on medication. I went in February and came out just after Easter with my son. My son was taken into foster care and I was referred to the Clyde Unit. I met several people with different problems there. The Clyde Unit has really helped me. I was here on the day it opened. I like the company there but only go twice a week now. I'm still on medication but not a very high dose. I don't know what else to say, I'll just leave it a that.

A large, bold black number '16' is centered in the image. The background is a grayscale collage of various human faces, similar to the one in the previous section, creating a textured, layered effect behind the number.

It started about twenty years ago, I had lost my father and I took it awful bad and turned to drink. At that time I didn't know what was wrong with me and of course you don't blame the alcohol, everything else but that.

I went to the doctor and asked for their help and I got sent to Hartfield

Clinic where I was seen a couple of doctors, but it wasn't what I was looking for at the time. I went back to my GP; he put up with me for a wee while then told me to get on with my own life and scored me off his list. I was left to my own devices with no medical help from anywhere. I had to re-register with a new GP.

When I went to the new GP's practice I saw a doctor, without even looking up at me he just said "if you miss one appointment we will score you off our list as well!" Then I started to see another doctor in the same practice. He really did help me, unlike the others who threw me away like I was trash. It was with his help that I came off the alcohol. I was given a CPN who came to see me at the house he came for a few months. He was also a great help, at the beginning I wasn't very committed to him because like a lot of people I thought there was nothing wrong with me. I realised that I had a problem and this nurse was great with me and I still keep in touch with him. I went to Lochgilphead for six weeks.

The medical help that I got when I came out of hospital, once they could see that I was trying to help myself was great, my new GP was very helpful. But at the time when I needed help the practice I was previously with got rid of me, and that didn't help me in any way. It just left me in a dilemma, with no doctor and no medication. Everything fell apart and I wasn't getting the psychiatric help that I needed because I didn't have a doctor to refer me. It was one hell of a nightmare!

After I got a new doctor and had "done my time" in Lochgilphead to get sober I got plenty of help. So far everything is going well. It's seventeen years since I had a drink but it did do a lot of damage to me physically and mentally. I still get psychiatric help from my GP. I'm quite happy with the system now but for five years I wasn't. Thankfully I'm on the right road, basically it's up to myself now but at least I know I've got the back up I need. Well I think I do! If I turned to alcohol again, which I hope to God I don't, some of the medical profession are not very helpful. They class it as an illness but it's not treated like an illness. You're just classed as an old drunk and they have no time for you, which is unfair as the person in drink is not the person you really are. One time I was really very ill and I got a taxi to take me to Gartnavel and asked them for help and they totally dismissed me, they wouldn't let me speak to a doctor and totally ignored me and I had to get a taxi home again. This was when I was without a GP. At that time I felt

suicidal, I was pleading for someone to help me but nobody would. The GP had actually scored me off his list and told me I was a waste of space and taking up a place for somebody that needed it and I was left in limbo. At the time when I went to Gartnavel they had an alcohol treatment unit, I don't know if they still have it. I went to them in a taxi when I didn't have much money to pay for it and literally pleaded for their help, but they sent me home. It was very hard then because I had no one to turn to.

I've started doing voluntary work three days a week now. My sobriety is very, very important to me. It's everything. If I don't have that I'll have nothing because at the end of the day I know that two drinks and I'd be on that slope again.

It's not until you get a bit better that you realise what's going on. Life is not easy as a sober alcoholic; I've got to take each day one at a time. I couldn't say I'll see you in a month because I don't know where I'll be in a month. You've got good days and bad days, some days I just sit and cry because I'm fighting wanting to have a drink of alcohol, but it's not as often now.

I've had a lot of mental illness along the way and sometimes I'm still not great but I've got to get on with it. Unless you have had problems you can't understand it. I turned to drink when my father died when I was seventeen. I was a daddy's girl and he was on a pedestal, I was too young to realise what was happening to me. It took me until I was forty-eight to learn. I could have had a good life, don't get me wrong my partner has put up with a lot and I've got a younger sister and brother. I must have been an embarrassment to them and my mother when she was alive. I've still got my brother and sister who I see or speak to every day. I've got my partner and four nephews, I would die for, who have never seen me falling about drunk which I'm very much aware of. I can't get up like a normal person; I've got to prepare myself for the day. I still see people who drank with me that are now much worse and I feel blessed that I got through it.



The first time I started feeling unwell was at the beginning of the 1980's when all the factories started shutting down. I had worked in three factories in the Vale of Leven and Dumbarton area. My parents started getting worried because I just couldn't listen to the news on the television.

My mother told my father to take me round to the doctor to see what was wrong with me. He gave me some tablets to make me feel like getting up in the morning. I had been getting up in the morning but I couldn't face anything, and I couldn't listen to the news because of all the unemployment. Going to my doctor made me feel a lot better. He told me to keep coming back from time to time. Time moved on and in 1983 I went down to one of the local keep-fit classes and joined in, I went for 13 years, one day every week, because I knew if I didn't go, I would be unwell.

Then we went into the 1990's and the Job Centre called me in but soon sent me away again because I couldn't find a job. They just totally dismissed me. I said to my parents: "that's not right, I've got to sign something to show for myself." I was awful worried about it and I kept going to the Job Centre. Then I forgot about it and stopped looking for work. The doctor told me not to worry about anything, but I was very concerned.

Nothing was coming into my life and I didn't know what to do with myself. My parents said "just come out with us and go to parties" but I said "God! Do you expect me to enjoy myself with this going on in our country!" My Father said, "Forget it! Forget it!"

About the middle of the 1990's I decided to write out my own CV and that made me feel better, looking at my own CV.

I was sent to Gartnavel Royal Hospital to be assessed, I was in for one month and I felt dreadful there, I really did feel dreadful. I didn't feel myself at all. I actually went back in time to when I was about 10 years of age. That was how it affected me.

They were very nice to me in Gartnavel and my parents came to see me.

Time went on and the nineties passed but nothing was changing for me. Everywhere I went people were nice to me but there wasn't any work, with even more factories shutting and I said "God! What's going to become of our country?".

Time went on and along came 2000 and I kept looking at my CV. I was doing a lot of work in the house as well, still taking care of myself: washing, cleaning and keeping myself tidy. Then my mother died, I couldn't believe my mother was dead. I said to my sister, beside the bed, "Oh, my beautiful mother!" and I burst into tears.

In April 2003 I joined the Clyde Unit, my sister had phoned me up and asked me if I'd like to have someone to come and see me. I said of course I would, I like people. I asked who's going to visit me? My sister told me that some people were going to come and see me in the house and I was glad to see them. It was then that the CPN started to come and see me and she made me feel happy again. I started talking to her about work and told her I couldn't stop thinking about working. Now I volunteer and that's good. The CPN came to see me every two weeks and she made me feel better.

After that I started to get up and go to the Clyde Unit every morning and I felt as if I was going back to work. Then the CPN stopped coming to see me.

I'm Schizophrenic. That's the reason the doctor gave me the tablets. I don't hear or imagine things but I do hear voices in my head going in and out of my mind. I don't have bad thoughts or dreams. I was told about three months ago what my dilemma was. It's like a nervous condition. I did feel a wee bit of relief when they told me.

The worst thing is the unemployment. It's good going to see the doctor and seeing all those people in the offices employed and working.

I've had lots of support, good support. I've got the Clyde Unit and I'm glad you are here today listening to me. Apart from this sad side of my life I've had a happy side. I've lived in Scotland for 50 years, I'm passed 50 now by the way, I'm really proud of Scotland. I'm a positive person.



I've come to realise that I've had a mental health problem since I was eighteen and I'm now fifty-six years of age.

My first contact with the mental health service was at Hartfield Clinic. They saw me for quite a while about thirty years ago. Then I went through life and was discharged from the system for a long period of time but I was reconnected back about twelve years ago. I had an accident when my ring caught on my finger and it severed it. I had to go to the Vale of Leven where a doctor diagnosed me with problems with my tendons. I had to go to the Royal Infirmary, I had booked a holiday at that particular time, and I was in there for two or three days to have an operation and had to cancel my holiday. The injuries I've still got to this day. I've got back problems, leg problems, peripheral neuropathy, and when I've seen doctors on different occasions, consultants, they said it was drink related. To this day I can say they are wrong, I definitely say they're wrong but that's beside the point.

I was admitted to Christie Ward six years ago in November and was diagnosed with severe depression; I was to stay in for six to seven weeks then be discharged. I just took it as a fact of life. I met a Doctor when I came out of hospital and I was under his wing for the best part of four years. The fact was day to day living was hard with clinical depression. I get lonely and I seem to suffer more and more if I'm in the house myself. Since I was diagnosed with a mental illness my wife has gone part-time and she can get the hours to suit me. I suffered a stroke in 2003, just over a year and a half ago, and I wouldn't wish it on my worst enemy. I was practically crawling along the floor. They took me to the Vale and I was in hospital for ten weeks

I was referred to the Clyde Unit about six years ago and I attend on three different days. I like to go to the unit to get myself out and meet company. Physically I'm not too fit but I try to get myself about as much as I can. I get myself involved in the groups and find it very supportive. I feel as if they after me. I find it beneficial getting company but I don't like being in large amounts of company. I feel as if I've got a problem I can speak to my named nurse. If it wasn't for the Clyde Unit I don't know where I'd be. They've given me the chance to get back to normality if there is normality. I don't know if I can say much more about my story but I hope you've got something out of me.



In October 2000, travelling back up from London, my husband took a massive heart attack and died. I had to go to the hospital but there was nothing they could do for him and then I had to come up the road and tell my two children and his family. In

the beginning I think I coped very well, I had to keep well for children. The first year I was just sort of numb, I knew he was gone but I couldn't believe he wasn't coming back. I had been to the doctors a couple of times and I just felt the longer the time went on the harder it was to cope. Then my own GP suggested I went to a bereavement group set up by the mental health nurses. I found it exceptionally good. It helped me because you were talking to people who had come through the same thing. You could understand the anger you felt and that it was quite right to feel anger as well as feeling sad and finding things quite frustrating. I found the group very good and the mental health nurses very good, the only thing was that gradually they started to change the group and different nurses came. One week one of the nurses that came said to me that it was ok for me because I hadn't had my husband very long, I'd only had him for twenty years and it wasn't as if I had had him for fifty years, which I think is the worst thing anybody could have said to me. It didn't matter if I had him for two years or fifty years, it is still the same. I tried to go for about a couple of months after that, but I felt I had absolutely no confidence in that nurse, if ever I had needed someone to speak to there is no way I could have spoke to her.

After that I became involved with the Mental Health Forum and started going to that, then I became involved with the Advocacy Service and did some training with them.

I find if I can laugh today I can be crying tomorrow. I presume it's just depression through bereavement, I was on tablets for quite a while but I came off of them myself gradually because I had put on so much weight. A lot of the tablets I was given I had been put on before for pain relief although they were antidepressants and they increased them over the time that I lost my partner. I knew what was wrong, I missed my husband so much.

My doctor was a help, but the problem was that there was one of the other GPs in the practice that I didn't want to go and see because I feel if he had given my husband the proper treatment he would still be here.

In the beginning the bereavement group, and the people taking it, were also marvellous. You went to the group for a couple of hours but you didn't have to stay all the time and it was very casual. There was always someone to speak to Monday to Friday, you could phone them up. The only problem was at weekends and at night when the only people you could contact were other people in the group, other people in the same position as yourself. There was no one available from the staff team to help you. There should be twenty-four-seven contact for anyone who is depressed, not just people struggling after a bereavement. Somebody that you can talk to in the middle of the night, sometimes that is the worst time in the twilight hours when there is nobody else around.



It all started about twelve years ago, I was admitted to hospital. I had great trouble trying to stop smoking and I was taken into hospital. They took me first thing in the morning and I fell asleep and when I woke up I thought I was in heaven. I was tied to the bed and I couldn't get up.

Eventually I found out that I was there because of my smoking and my illness. I had breathing problems and at that time I was operating a Small business, there was nobody to take care of the business except me and my wife and it was just too much for one of us. I had to go back to work right away. I didn't get any time off, I tried to take time off but I was forced into going back to work too early and I tried to commit suicide, I tried to go to the Erskine Bridge to jump off. When I went back my wife found out I'd tried to commit suicide, I admitted it to my wife, and I was eventually taken to Gartnavel Royal and locked up in a secure ward. There were bad experiences, somebody kept following me about - this young man about thirty—and it wasn't until later on that I found out I was on suicide watch and he was a nurse, not another patient. I thought he was another patient and that he wanted to fight with me or knife me. I would have preferred it if they had their uniforms on, the nurses. Then you could distinguish who is who. You were frightened to talk to anybody and it took me quite a while to work out who was who.

I eventually got out of hospital. I had employed somebody to work in the business but I couldn't afford to keep them on and I had to go back to work myself. The business was becoming a great problem to me, I was picking up small problems and making them into large problems and I was being very aggressive, not fighting, but having arguments. I ended up going back into hospital again. I've been locked up five times and that's enough. It got to the point that if I asked to go back into hospital then they would just take me back in again. I found I got to a certain point in my treatment then I never seemed to get any further, I was always having these problems

I ended up fighting with my wife and my family life got so bad that I ended up in a flat of my own and I stay myself now, which is why if a problem comes up now there is only one person to solve it and that's me. I blow things out of proportion. Sometimes I don't want to go out and other times I don't want to stay in. It's like if someone says something's going to be on for three hours I'm ok, but if they say one hour and it runs on, I want to go home. I don't want to stay, I don't want to dwell too long on one problem. I want to go and do something else.

I'm diagnosed as being manic depressive. I think I was sitting with the psychiatrist and my wife having a three way conversation when I was told. I've got a great difficulty hearing and I miss a lot of things that people are saying. I think the wife relayed the conversation to me. No one told me what manic depression was. I went and looked in a dictionary and some of the things I do are part of the illness. Yes, it would have been better if they explained it to me. I have suicidal tendencies. To me that's the most serious of illnesses. I haven't self harmed for a while now but I still get the thoughts and they get worse and worse.

When I started self harming the only advice I got was "stop doing it", but to me self harming is the same as being an alcoholic or being hooked on cigarettes. If it was that easy to stop you would just stop it. I've not got anybody to advise me what to do. I've just to sit on my hands, what do you do when you're self harming? That's one of the things in the health service I would like looked at. They have not got any person that you can go to for, I don't know, peace and quiet. We've not got anywhere you can go and recharge your batteries, we need a place like that in the health centre out of hours. I've been told that

between 9 am and 5 pm I can see my CPN if I've any problems and I can go to hospital if I've any problems during the night. I went to hospital one night and asked them to take me in so that I could see the doctor but they refused and I was frightened to go back down the road again because I had to go past the bridge. I feel that the second time I will do it. The only thing that stops me doing it is that there won't be any coming back from it.

I'm getting better now because I've not got anybody to upset, I only go to see my family when choose to see them, I go to them in a good mood. My wife said to me I should go back home again but I don't want to go back home I'll just stay where I am. I couldn't face breaking the home up again.

I haven't got any complaints against any individual. Nobody has been bad to me or abused me. I stand by everything in the National Health Service, but some things need to be put into place to make it better than what it is.



I was actually living in Ireland at the time, in the Republic of Ireland, and I had a long term relationship. Through stress I ended up in a psychiatric hospital in Ireland. My girlfriend at the time got the doctors and nurses to come and see me because I was so unwell and I ended up in the psychiatric hospital. At the point when I was becoming well she didn't want anything to do with me, she probably thought I wasn't myself. I also thought I wasn't myself. While I was in the psychiatric hospital she said she was going to end the relationship. I thought this was a joke but she did end it. I had no support then, I had no friends and no family in that part of Ireland so I ended up in this house on my own and I became unwell again because I stopped going for my injections. At that time I had to go to the doctor for a prescription, go to the chemist to get it and then go back to the doctor for the injection. It was an absolute nightmare, it was just too much for me. I ended up five months without my drugs and that's why I became unwell again.

I wasn't well and kept hearing voices and one day it came to a head when I left my bed-sit and started off for Dublin. I got to a place called Dundalk and I had no money because I had spent the night in Belfast and had used my money in a bed and breakfast. I was sleeping rough and these policemen took me to Larne and a policeman in Larne got me a ticket to Stranraer. I ended up going from Larne to Stranraer on the ferry and when I got there I just started walking. I got to Ayr and spent the night in a bus shelter. The police picked me up and put me in the jail for a night and gave me something to eat, they got me fish and chips at three o'clock in the morning!

The next day the only phone number I had was my dad's, I had no one else's phone number or address, this was strange because I hadn't spoken to my dad for years. I stayed in the jail for the night and then my family came and got me and bought me a meal. I was at my dad's house for two nights but I wasn't well. I was getting up during the night and walking down the road in my socks with no shoes on. The doctor came to see me and he sent me to Gartnavel Royal Hospital, to a ward full of really unwell people. I suppose I was really unwell myself. They gave me drugs and put me out for three days, I don't know why they do that, but I am pretty sure it was for three days. I got back to taking my medication by injections. I got back in touch with my GP and they put me on new medication but that wasn't really working so they put me on something else and that was a wee bit better, although it meant I had shaking legs, staring eyes and saliva drooling, that was horrible. I was just a wreck. I went back into hospital for about three weeks and I was put into a ward where the people weren't quite so unwell. It was in that ward I told a student nurse about my condition in Ireland. She went away and then came back and asked me if I knew what my diagnosis was. I said "I don't have a clue", and she told me I had Schizophrenia and I thought "Oh, my goodness!" At the time I wasn't sure how to take it, I think I would have taken it better from a staff nurse or a psychiatrist or something but it was a student nurse that told me. She has since qualified. It was her that told me I was a schizophrenic. It was hard to take the diagnosis and I was angry it was a student nurse instead of a psychiatrist who told me. At the time I was shocked, my CPN said he would get me information on my condition and I still read that book at least once a year. I realised I wasn't as ill as some people, but it makes you feel really sad. A lot of people lose hope. We don't realise everybody else is as messed up as we are!

I had a few jobs in Ireland. Is it alright if I go back a bit? When I was living there I was working in this big factory for people who were mainly people with learning difficulties. So that really wasn't the place for me. I did a few stupid things then and that's when I ended up back in Scotland. I was put in a hostel for people with mental illness. A few places rejected me, I don't know why. I don't know if I was too severely ill or not severe enough.

Then I applied for a house in Glasgow but they told me I had made myself homeless so I couldn't get a house there. Eventually I got a house in Dumbarton. It was a flat, but I had a few difficulties because I had the shaking legs, staring eyes and saliva. I wasn't fit for anything really. I was there for about three years, the neighbours didn't like me, there were about twenty or thirty young guys hanging about and they used to throw bricks at my windows. I suffered this for about a year and I was a nervous wreck. I went to the housing and asked for a house away from that area and I got the house I'm in now. It's taken me years to get it into the condition it's in.

It's was about that time that I went through lots of different psychiatrists and I hated that. Every six months the doctors would change and I couldn't get any stability the only stability I had was my GP. With all the different prescriptions it was too much, so I ended up unwell again. I was attending Gartnavel outpatients; I was doing a bit of art therapy, cooking and all sorts of things. I went to see the psychiatrist and he asked my if I would try a new medication. They had to take you into hospital to start it and said they'd let me know as soon as a bed was available. I got a phone call the next day, I was in for thirteen days as a day patient just to check I was ok and to check my white blood cells, and its been working out. It made me more confident, the shaking legs and the saliva and staring eyes have disappeared.

Since then I have been trying to lose my weight, and I've been working for about two years as a volunteer. I got involved with Activate and that was good, I taken part in writing groups, art groups and the Mental Health Forum. You have to socialise, you have to get used to going to the pub or going for a meal in a restaurant and it's very tough if you've been through hell.

The thing with mental health services is that every six months you must do this, this, this and this and I just can't do it. I don't react well to change. I can't change my whole life, maybe they want that but I feel

it's just too stressful. You would go to one group for six months or six weeks and then something else and it was just too much.

I found some of the staff really nice in Gartnavel Royal and in the Clyde Unit. People who treated you like a human being.

Common Themes

The experiences of the twenty-one people who shared their stories as part of the "Mental Health: What's the Story?" Project are unique to each individual. However, a number of common themes emerged.

Crisis and Out of Hours Services

A significant number of people said they felt isolated and unable to access support they needed in the evenings and at weekends. Some people felt that if they had been able to access support when they felt they needed it most it would have helped them to avoid becoming more ill and requiring hospitalisation.

"I've had one really bad experience when a friend of mine was unwell. All weekend I was trying to calm this girl down until she could see a doctor. It was a bank holiday so we had to wait until the Tuesday Morning. On the Tuesday she saw the doctor and had somebody to talk to all week but on the Friday off she went again. I managed to get her to see an on-call doctor but she wasn't so bad she needed the hospital and he sent her home again. I was just left to get on with it."

"What we really need is a 24/7 service, there when you need it. Even a help-line or something, you hear this from everybody."

"It's terrible at night time and weekends when you have nobody to talk to, nobody who understands."

"Monday to Friday I can cope with but at the weekends there's nothing. Night time is the worst, during the day I go to groups and meet up with people but at night time its worse. That's the longest time."

"I always seemed to take unwell on a Friday night, I think a phone line, just knowing somebody was there would have helped."

Continuity of Service

Most of the twenty-one people who were interviewed talked about the importance of continuity and the difficulties and anxieties caused by recent changes and continuing uncertainties affecting mental health

service provision in the Lomond area.

"You keep seeing different people, psychiatrists I mean, you see them a couple of times and then they go away. Then the next one hasn't read your notes and you have to go through your story again, talking about things that are really upsetting."

"There should be a Community Mental Health Team in place. Then you wouldn't have to continually tell your story to different people, getting nowhere."

"During my stay in Christie Ward some of the nurses were really good but it was at that time when all the psychiatrists were resigning. I was really unwell and I had told the psychiatrist lots of things. I had confided in them, told them things about my childhood, personal things. All of a sudden they were away. I was given another psychiatrist but I never went back to talking about things again, I just thought what's the point. I can't do it all again."

"I don't know how many times I've had to go over the same thing. Even my date of birth, my name and things. Do they not read the notes. You shouldn't have to keep going over the same thing with different people."

"The worst thing is all the changes, the uncertainty."

"I think they should get permanent psychiatrists. The way it's been with locums is no good. I understand that changes have to happen sometimes but it's a worry. I want stability."

Involvement and Information

Several people talked about the importance of being informed and feeling involved. People expressed a desire to be involved in decisions about their own care and treatment and also having a say on wider decisions about the provision of mental health services. Lots of people thought more should be done to promote understanding and tackle stigma

"I started to get involved with groups. I was asked by someone to go to the Mental Health Forum...I went to see what it was all about and was

pretty taken aback by all the business. Since then I've got really involved in committee work. I feel more involved in the community and I can help other people and have more responsibility."

"We're not taken seriously enough. I feel it's tokenistic. I think they only have us on panels and things because the Scottish Executive has told them they have to. Users should be listened to seriously, not just be bums on seats!"

"People just can't understand what your illness is. If you've got a broken leg people see it, if its in your head they can't see it and don't understand."

"I would like to see more education, starting with schools, there is so much stigma out there. People think if you have a mental health problem you are stupid and dangerous"

"From my husband's point of view I don't think there was enough information, and maybe some material for the kids to understand too. Somebody to explain why mummy was doing these things, my husband had enough trouble trying to understand himself, he couldn't put it into words for the kids."

"No one told me anything. I looked at the notice board and saw some leaflets on manic depression and schizophrenia. I took them both and read them. Everything became clear to me, it was as if somebody had switched the light on. It was all explained in the leaflets, everything came to me, why I was like this. If I hadn't picked up those leaflets I still wouldn't know what was wrong with me. I would still be toddling along in the system with nobody telling me what was wrong with me."

"I said to the nurse "What's wrong with me?" This was eight, maybe nine years, after I first took ill, and he just laughed. I said "This is serious. Am I going to die?" He said "No, your not going to die, we're treating you for manic depression". I said what's that? How am I going to deal with it when I don't even know what it is?"

Diagnosis

A significant number of the people interviewed did not have, or were of their diagnosis. This included people who had enduring mental health

problems who had been using psychiatric services for many years. Others who did have a diagnosis made comments about the manner in which it had been received.

"My diagnosis came piecemeal; I picked up bits here and there. Nobody ever said you have such and such. I tend not to like asking doctors questions, just like a lot of other people."

"I've had it a long time, it was 1985 when I first went in (to hospital), but I don't know what it is, no, I just don't know."

"One day they told me the anti-depressants might increase my rapid cycling Bi-polar Disorder. That was the first time I heard my diagnosis, I presume he thought that I already knew. I had my suspicions because I like to find out information about my illness, probably because I have a medical background, and I thought my symptoms were consistent with a Bi-polar Disorder. Nobody ever sat me down and told me what my diagnosis was, it was just mentioned in the passing. When I did find out I felt relieved because I knew then that I wasn't just bad tempered. I had always thought people didn't believe me when I told them the things I did. Now I know it's just part of my illness."

"When I first got a diagnosis I couldn't believe it. It's only over the last year and a half that I've settled down to it. Acknowledged that I have an illness. I'd gone to university, I was a manager, I thought don't be ridiculous, I can't have a mental illness. Post-natal depression was more acceptable, even though my child was seven. I prefer Bi-polar, manic sounds like a mad person."

"One day I was in the psychiatrists office and I saw a wee book. I asked if I could borrow it to read. A lot of information you have to go and find for yourself."

"I think I was diagnosed three years ago as "slightly backwards". The GP referred me to a CPN who was going to re-refer me to someone else but I've had no contact since, so I don't really know."

"I didn't know what was wrong with me but then I saw it written down in one of the letters in the office. It said "Anxiety Neurosis", I just thought I was totally away with it, you know?"

"It was quite a relief in the end to find out what was wrong with me, to be able to understand why I acted so differently from other people."

"I kept asking questions. I wanted to know what was wrong with me. The nurse said I had to take this pill, I asked why and he said, "Because it says so in your notes". I said "tell me my diagnosis but they still didn't tell me. I would have felt better if they had told me. One of the nurses was very good. He used to answer my questions, so I kept bombarding him with more questions to find out for me. It was through him that I found out what the drugs were for."

"I finally got a diagnosis from a psychiatric nurse who asked me if I knew what was wrong with me. I said "why didn't they tell me this two years ago?" I said "tell me what it means in words I can understand." She did her best to explain but when I get upset I can't take things in. My daughter got me some information from the internet but I think its wrong that we had to resort to that."

Conclusion

Although many of the people we interviewed spoke about bad experiences and a sense of injustice, most were also keen to offer praise for the support, assistance and understanding they had received from a wide range of individuals, agencies and organisations. People paid tribute to the hard work and dedication of professionals, friends, family members and fellow service users.

"They (support services) are the best thing that has ever happened to me. I wouldn't be here without them."

"Everybody has their own personal hell. I think of mine as a tunnel, others talk about a fog or a black hole and it can feel like that too, but at least in a tunnel you can sometimes see the light at the end."

"Nobody chooses to be mentally ill. It can happen to anybody. I never thought it would happen to me. People should think about that. Think about how they would want to be treated if it happened to them."



PART FOUR:

Appendices

The Project Team

The "Mental Health—What's the Story?" project team consisted of four researchers, all of whom had direct experience of using mental health services. The researchers were from a variety of backgrounds and differed in age. They included two men and two women. Some of the researchers had been in contact with psychiatric services over many years and had experienced hospitalisation, whilst others had had a relatively short time in "the system". The project was facilitated by two workers from Lomond & Argyll Advocacy Service and a Social Worker/Mental Health Development Worker employed by West Dunbartonshire Council.

One of the recognised benefits of user-led research is the therapeutic impact on participants. Participants took part in a range of training, on a weekly basis, over several months before undertaking the research. The project evaluated the experience of those involved at various stages. Participants have made the following comments:

In relation to advocacy training:

"nervous at the start"

"never done anything like it before"

"very interesting"

"I learned something new"

"I can do it!"

"It raised my self awareness"

"It made me think positively, I now know I have the right to question things"

In relation to user focused monitoring/research:

"I was initially anxious but became more confident"

"I felt tested"

"By doing this I have gained experience"

"It was fun. The group experience was good and we developed a lot of trust in other participants and shared a lot with them"

In relation to the interviews/research:

"I was surprised so many people came"

"I felt humbled because people were prepared to share their pain"

"I felt privileged to be part of it"

"I learned a lot about myself"

"People didn't feel they were being judged or assessed, they were open and honest and gave strength to each other"

"I enjoyed it"

"I felt angry at the injustice people experience"

Since taking part in the Project all four participants have become more active in the user/carer movement. They have made the following comments about the consequences of their participation in the Project:

"I feel much more confident"

"I would like to take part in other projects"

"It has been a cathartic experience for me"

"I realise that the "experts" can sometimes get it wrong"

"It gave me hope"

"I feel more motivated to do other things"

Summary of advocacy and user-led research training course

Training was based on an adapted model of Lomond & Argyll Advocacy Service's "Basic Advocacy Skills" Training Course. The content of the course was recently commended by The Advocacy Safeguards Agency during an independent evaluation in 2003, who commented:

The course is based around five modules and was delivered over eight two hour sessions:

Module 1

- The group introduce each other and the course objectives are discussed
- The group discuss their hopes and concerns regarding the course. This includes producing a list of ground rules
- The group go through a questionnaire filled in by participants prior to the course. This helps people think about their strengths and areas for development, and helps people prioritise their learning needs.
- Discuss what advocacy is and is not based upon a list of statements (for example, it is understanding what the service user wants, but it is not telling the service user what to do)
- Watch and discuss a video about 'effective' and 'ineffective' advocacy practice
- Complete listening skills exercise to get a better understanding of participants own listening skills

Module 2

- Go through the results from the listening skills exercise in Module 1
- Exercise about power and helplessness. This takes the form of a role play called 'visiting the director'.
- Watch and discuss a video showing a 'typical' advocacy scenario. This is called 'we have the right to be together, don't we?'
- Exercise about questioning and probing
- Exercise about increasing active listening skills
- Discuss non-verbal communication
- Exercise where the group practice their questioning and probing skills

Module 3

- Exercise about understanding the limitations of verbal communication
- Exercise about understanding empathy and responding to other people's problems. This considered as if from an advocacy client's perspective.
- Role play exercise based around case studies. About increasing skills and confidence in building relationships with, and getting information from, service users.
- Exercise around non-verbal feedback of course participants. Discussion around appropriate feedback.
- Video-based exercise. Participants watch examples of 'effective' and 'ineffective' advocacy and mark according to techniques learned on the course so far. Also a discussion on empathy and gender roles based on same material.
- Exercise about client expectations based on case study.

- Activity covering discrimination and prejudice issues.
- Exercise about the differences between perception and reality
- Discussion about rights and responsibilities and when these may conflict.

Module 4

- Exercises about people's perceptions of words and their meanings and how people perceive and remember.
- Exercise about understanding why put-downs are used and giving people the tools to deal with them.
- Discussion around working with power.
- Discussion around negotiation and conflict resolution.
- Discussion around dealing with 'put-downs' and dealing with anger.
- Exercise around how to learn from unsuccessful advocacy situations

Module 5

- Exercise on gathering information
- Practical concerns from the group.
- Discussion around what happens next for volunteers
- Background to the Community Care Act & other relevant legislation
- Available library books

- Discussion of 'advocates handbook', LAAS leaflets etc.

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This Report quotes directly from a number of sources which are listed below.

In addition, Part One of the Report, in particular, draws heavily on a literature review published by Partners for Change (July 2002) entitled "*User and Public Involvement in Health Services*", which was commissioned by Scottish Human Services as part of its work for the Scottish Executive.

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Mental Health :

What's the Story?

A User-led Research Project

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