



**College of Psychiatrists
of Ireland**

Wisdom • Learning • Compassion

On the One Road to Recovery

A paper written by REFOCUS (CPsychI)

Foreword by Dr Anne Jeffers,
Director, External Affairs and Policy

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To the members of the College of Psychiatrists of Ireland

In November 2011, the first meeting of REFOCUS (Recovery Experience Forum of Carers and Users of Services) was held. REFOCUS is made up of 10 people with experience of mental illness, and ten people who had family members who used the services. The aim of the group is to “Actively engage with the College of Psychiatrists, in order to improve the education of psychiatrists, and thereby improve mental health services”. The group is jointly chaired by myself, and by Kevin Jones, current Secretary of EUFAMI. Andrea Ryder and Sibeal Farrell provide the group with administrative support.

From the beginning I have been hugely impressed with the dedication and commitment of REFOCUS members. Last March the College launched “*Who Cares - Hearing the needs of people who care for those who use mental health service*”, a paper written by service users and carers, around the needs of family members. This paper is available on the website, and all members have been encouraged to use it in their everyday practice.

I am very proud to present the latest paper from REFOCUS, “*On the one road to Recovery*”. It has been my great privilege sit in on some of the meetings during which the paper was written. The group members were open and generous in sharing their experiences, they were hugely supportive and understanding to each other, and made every effort to ensure the paper would help psychiatrists as much as possible. Their ability to reflect and understand their emotional world was both impressive and humbling. The group was amazed to hear that reflective practice had only recently become regular practice for psychiatrists.

While the group set out to write a paper to help trainee psychiatrists, it will also be of help to all who experience mental illness and to their families.

I wish to thank the group for giving us this paper, which I am sure will enhance the practice of all who read it.

Yours sincerely

Anne Jeffers

Director, External Affairs and Policy

September 2013

REFOCUS CPsychI

On the One Road to Recovery

A paper written by the service user sub group of REFOCUS CPsychI

Introduction

This paper is prepared by a subgroup of REFOCUS. The subgroup is made up of people who have had experience of using mental health services. All are currently living fulfilling and satisfying lives, and are in recovery. We write the paper for members of the College of Psychiatrists to hear our stories, and to hear what has worked for us in Recovery.

We began this paper by each of us writing about our own personal journey to recovery. We then, through focus groups and discussion, teased out themes which were emerging. Narratives and specific anecdotes were particularly powerful in helping the group understand what each person had experienced.

Most of us have had very positive experiences with psychiatrists, and this paper is seen as an aid in helping psychiatrists reflect on their practice.

We are aware many psychiatrists see their role as sorting out problems. In this paper we make suggestions on how the psychiatrist might be there to facilitate the service user in sorting out his or her own problems, as for us, this has been what has worked in our recovery.

The following analogy explains this well:

Being mentally unwell is comparable to being in a ship in a storm at sea. In this distressing situation the psychiatrist, instead of taking over the captaincy of the ship from an often mutinous crew, should instead be more akin to the beacon of sanity from a distant lighthouse, cutting through the confusion of a troubled mind and offering the hope of a safe landfall. In this way the person experiencing the distress finds their own way to port but not without the invaluable assistance of a concerned professional.

From our discussions on the factors that have contributed to our recovery, five main themes have emerged:

- (1) Acknowledgement that there is a problem, however one defines that problem
- (2) Taking ownership of that problem
- (3) Taking action to deal with the problem and maintaining autonomy
- (4) Believing that recovery is possible.
- (5) Lifestyle changes and/or learning from the experience to prevent or ameliorate a recurrence of that problem.

Another analogy helps explain these themes.

Firstly, If we define emotional upset as being equivalent to a pothole on the Road of Life. If the pothole is small, more often than not we will negotiate it successfully. We might, however, twist our ankle, which could result in a weakness in that ankle where the problem recurs in an ongoing basis. Alternatively we might negotiate the minor potholes until we come to a major pothole where we could break our leg. Obviously, if we do, we acknowledge that we have a serious problem i.e. we can't walk. We take, as we must in this situation, ownership of the problem, by recognising that it is our responsibility and in our interests to get better, so we may go to a doctor to have the leg set. We have alternatives if we distrust doctors, such as alternative medicine or going to a bonesetter if we feel we have choice then we take ownership and action to deal with the problem. The recovery period may require a large amount of rehabilitation and the leg may never be fully right again but we regain autonomy and gradually strengthen it by physiotherapy and walking. Even in the event of a full physical recovery though, we will probably never approach a pothole in the same way in the future- we will either recognise the problem i.e. the pothole, and step around it, or where it is unavoidable we will use what we have learned from previous potholes and hopefully, negotiate the crisis. If we have failed to learn from our experience the likelihood is that we will break a leg again. Therefore, seen in this light, recovery never means 'returning to a former state of being' - our physical state may return but we are irrevocably changed mentally by our experience.

(1) Acknowledgement that there is a problem, however one defines that problem

When a person comes to a psychiatrist and explains their experience, we have found what helps best is when the psychiatrist listens, and acknowledges that what is described is the individual's reality, and then helps the person look at how this reality may be incorporated into their lives. Many of us have found the Stress/Vulnerability Model useful to describe how we may be experiencing problems. The more vulnerable a person is, then the less stress it takes to develop symptoms. This approach appeals to us, because this also means that the more resilient one is, the less easy is it for symptoms to develop, and it gives us more of a sense that we can influence the symptoms ourselves.

For some of us, being given a diagnosis, with quality information on that diagnosis has been very valuable. For some of us, the experience of being told we have a chemical abnormality has been disempowering. This is so if we are also led to believe we cannot do anything about it ourselves. It has left us feeling there is nothing we can do to control the symptoms. It has taken away hope. Any discussion around chemical imbalance should also include what can impact on that, such as exercise or reducing stress, helping us to understand what we ourselves can do to improve the situation.

“The language used by the psychiatrist is very important. Some service users are emphatically opposed to the chemical imbalance paradigm and their views should be respected.”

We have found we are all unique in how we make sense of our experience. For all of us it is important that the psychiatrist hears our story. The narrative can be key.

“Psychosis can be like a dream, but there can be a logic in it, it can have links to reality, and if the psychiatrist can help us, through talking, to identify how this makes sense to one's self. It is important to be able to see the links with our experiences and reality, how we are not mad, but that our experiences can be linked to some trauma or event. It seems as if it is putting the cart before the horse to describe a chemical imbalance. It can feel as if we are totally misunderstood.”

We have discussed this piece as a group. Some questioned whether the word “mad” should be left in or not. Some have concerns that it can be seen as pejorative, others wanted it left in, to emphasise that when it is your own reality, it does not seem abnormal, and one person commented.

“The point is - you never completely give up your own view. Part of you never relinquishes your alternative reality, if you can find a way to manipulate it into a recovery perspective that is what is important.”

How the diagnosis is communicated is important - the psychiatrist has to show he/she understands what the person is going through. The language used is so important, and the psychiatrist needs to take time. Explain everything in detail, and at all times give the person an understanding of how the illness may

progress. We suggest that you don't say things like "you will be on medication for life..." or "you will never be able to ...". We strongly suggest you minimize the hopelessness and maximize the hopefulness. Even the worst diagnoses can and do have positive outcomes. We find it much easier to deal with a condition, with particular explanations of how you as the psychiatrist reached your conclusion rather than being given a diagnostic label.

We would also want information on what is likely to happen, what the medication does, and what the literature says on what would happen after a certain period of time if we came off medication. We need information on what alternative therapies do, how talking therapies work or don't work. There should be options other than or along with medication used to help us with our difficulties.

"We want to work with you in ensuring we can get as well as possible. We would like you to focus on what we see as important. Sometimes symptoms, such as hearing voices, or being paranoid, may not be causing us distress, but managing money, or getting by day to day may be the problem."

Recovery is living a fulfilling and satisfying life. This is not necessarily living in the absence of symptoms. Recovery is possible even in the presence of symptoms. We know there are times when there is denial by a person with a condition that there is something not right and resistance to seeking help. The psychiatrist needs to try to understand where the resistance is coming from, try to persuade rather than force, to understand rather than reach conclusions too quickly.

"A man convinced against his will, is of the same opinion still."

Once the psychiatrist gives that first diagnosis, or discussion on the condition, there is a need within a few days for someone on the team to contact to know how the person is coping, and to go back over the information. If the service user consents there is also a need to address any family issues early, and assess how the family are coping. Mental illness is a life changing experience, both for us and for our family, and all parties need to be aware of this. It is rare for the person to return to their former self, and this poses challenges for all.

(2) Taking ownership of that problem

The psychiatrist and the team should do as much as they can do to work with the person and encourage them to take ownership of the problem. This will be best achieved by understanding what the person is experiencing.

"Bloody-mindedness should be seen as strength"

Psychiatrists need to work with a person's resistance. If they give up their medication six times, there must be a good reason for this. Instead of seeing it as a problem the professionals need to acknowledge there has to be something in it if the person is repeatedly giving the same message. The psychiatrist needs to listen carefully and negotiate.

“I found it really helpful when my psychiatrist said, ‘you want to stop medication, good, what are you going to put in its place? I felt I was being treated as an adult’”

This type of conversation helps to put a plan in place. It can help with a gradual reduction in medication and with a clearly identified plan if any deterioration occurs.

Psychiatrists need to be more open about why they are so cautious of taking risks with medication. Conversations around risk will help the patient understand more about the problem, and can also reassure the psychiatrist on risk. Think of our metaphor of the ship, as the patient steering the ship, we need to know about the risks, but we are the ones who can best negotiate them.

“I would prefer to manage my own risk”.

We would prefer discussion around “appropriate care” rather than risk management. We suggest a judgement is made around capacity, and if the person has the capacity to make decisions this is respected. If they do not have the capacity, then these are times when a psychiatrist needs to be directive. An advance directive, written with a professional or peer support worker, would help in this situation.

Psychiatrists can help with ownership by helping the patient to understand what is happening. This helps to make us more self-aware. It is more helpful if the psychiatrists make suggestions rather than give directives, such as asking “Have you considered” Encourage an atmosphere of trust and comfort to enable someone to work with a psychiatrist to gain ownership and have a say in their own recovery, with the psychiatrist guiding, suggesting and signposting rather than directing, threatening or telling someone what to do.

Diagnosis, whether it is with cancer, or mental illness, can have a different outcome depending on the attitude of the person who is ill. For many of us, we can accept the diagnosis but there is a refusal to accept what we see as traditionally negative prognoses. Information, help, support, and self advocacy can all help the individual get to a point of thinking or saying

‘It’s a problem, and I am determined I am going to sort it out’

(3) Taking action to deal with the problem and maintaining autonomy

We have all got better when we took responsibility.

“For me, recovery was about letting go of the anger”.

We are aware that the anger of having a problem can lead us to take it out on our doctor, and at times we can be very critical. We have all met really good psychiatrists, and we have all benefitted from their input. What follows are some suggestions which might make that recovery journey easier. We are also aware we have all had different experiences.

“I have been really impressed with the young doctors, they really know their stuff, and are good listeners.”

For others they have found the trainees are more likely just to focus on medication, and they found the older Consultants more likely to listen.

“Older Consultants seem to be more aware of the need to look at the whole person; they seem to be more empathic”.

When we go to a psychiatrist we want full attention - don't text or be watching your mobile phone - don't be writing notes into the computer while attempting to listen. This is a difficult interview and this needs to be acknowledged, however far along the road the person is. If we want a carer or family member or an advocate involved, this needs to be respected.

We have all had experience where we have felt rushed, almost as if we are a nuisance, and sometimes, as adults we have felt we were treated as children. We have also had experience of really being listened to, and have left an interview feeling very positive. Trust is the key - we are not going to divulge sensitive information initially or at another meeting if we are not comfortable trusting the psychiatrist or feel if we describe behaviour or symptoms that the only action will be to increase the medication.

“I would say nearly every psychiatric patient has lied to their psychiatrist at some time. It is not that you want to deceive, but you know if you admit to hearing voices, or other symptoms, they are likely to increase medication, or admit you to hospital. You also know that they believe so strongly in medication, that when you admit to not taking it, even the psychiatrists who will talk, and who are easy to talk to, will still try to convince you to take the medication. You learn to say what they want to hear.”

We need to know there will be support when we need it. That we can talk about symptoms of relapse without the fear that we will be forced back to hospital, or forced back on medication. That we can have an honest conversation, including that we may have stopped medication, either in error or by design, and that admitting that will not stop us from receiving treatments. When we have capacity we need to be able to make our own decisions, even if the psychiatrist does not agree, and even if some of these decisions turn out to be wrong. It works both ways. If the psychiatrist trusts the patient, then he will trust the psychiatrist.

“We want psychiatrists to use more friendly open questions to get a discussion going - this should be a communication between two people, - don't pry for proof of symptoms - don't make a big deal of symptoms which could have the effect that someone won't admit that they have been experiencing them.”

Focus on what distress the individual is describing, and acknowledge that distress. Take time and ensure other team members are involved.

“I would like acknowledgement of some of the positives of the experience of psychosis, more compassion and help to gain better insight into myself. Being allowed to relapse had its benefits in helping me understand myself better.”

For many of us taking medication helped us, and we were able to get on with our lives. But it was important that we could learn that for ourselves and not that we were only taking medication because we had no choice.

For many of us, our family is the main support, and so we want them involved in our care. However, we are very clear it is our problem. There are not three equal parties in the relationship. Some of us have found our families' ideas of recovery are unrealistic. In some cases the family just wants the person back to the former self before the onset of illness whereas the person who has experienced the illness finds they have changed, and often grown from the experience.

“My family believed just in the medical model, I had done a lot of research, I was better informed than they were, but they found it hard to accept my view. They felt more confident in accepting the view of the professional expert. They did not see me as an expert.”

We acknowledge there can be great stress for families, but we would ask that psychiatrists separate out the family issues from the individual's issues. Some of us have found we recovered better once our family stepped back.

Hospital Experience: We support the New Zealand Mental Health Foundation statement -

“Our health improves more quickly if we are calmed rather than restrained.”

The discussions on hospital experience brought up many emotions, particularly when restraint was discussed. Many of us have not been restrained ourselves, some of us had very positive experiences in hospital, some of us felt vulnerable to being restrained in hospital, and it was only very strong advocacy that prevented that. We all agree that aggression and violence can be minimised by negotiation and a certain approach, everything needs to be done to avoid detention or brutality in hospitals. For many of us being held down to get medication, being restrained or being put in seclusion has had a major effect on our ability to trust psychiatrists or nurses.

“being restrained and put in seclusion had an immensely damaging effect on me.”

“When I was in hospital, the majority of nurses were great, but there were a few, and when they were on duty, restraint was more likely. Looking back, if those nurses were not there I think I would have got much more out of my hospital admission.”

For many of us having a hospital to go to when unwell is really important, and the experience has been very positive. Getting away from the stress of a family situation can be important.

“I liked my family visiting when I was in hospital, but getting away from the stresses of everyday life was so important”

For others staying at home, and feeling we were still in control of our own situation was important. Choice and getting it right for the person at that particular time is what it is all about.

(4) Believing that recovery is possible

“ I remember in the early days when I felt no one understood what was happening me, I met one registrar, I can't remember what she said, but I always felt she believed I could get well, and she seemed to be able to focus on what I wanted to do and my strengths, rather than just about diagnosis or medication. It was a pity I never saw her after discharge”.

Many of us believe the key to our recovery has been acknowledging that “it is not the end of the world”. Yes it may stop us from doing some things, but there are still a lot of things we can do. An acknowledgement and acceptance of this fact has been so important. All services should emphasize the belief that the person can have a fulfilling and meaningful life, even if it is different to pre-illness days. Indeed it can often be a better life.

“I may not be able to become an astronaut, but I may become an astronomer”.

In helping a person identify goals, the focus should be on ways to stay healthy, ways to get on with one's life. This focus, rather than the focus on illness and symptoms, is what has helped all of us recover.

“It is about helping us with an attitudinal change, we may need to change our expectations, make adjustment to our life, but even in an impoverished environment, we can lead a healthy life”.

It can be devastating to be given a diagnosis that we are told is life-long. For example with schizophrenia, we now know that many people recover fully. Emphasising what can help to prevent the condition becoming long term (where this is known) is important. Emphasising what can prevent the challenges of our illness overwhelming us is important. Focussing on strengths is important. Learning how to use those strengths in helping us to get well is important. Getting back to education has been a positive in many of our lives. Working and being in supportive relationships has also helped. Psychotherapy has helped many of us. It has helped us gain an understanding of how we can take better responsibility for our own Recovery. Having one person working with us over a period of time is helpful. Seeing other people recover has also been very powerful.

“I felt validated in my experience, when I met someone else who had been through something similar. It is so much easier to believe in yourself, if you can see someone else further down the road of recovery”

(5) Lifestyle changes and/or learning from the experience to prevent or ameliorate a recurrence of that problem.

Some of us have found spirituality a great assistance in Recovery, and yet it never seems to be asked about by the psychiatrist. We advise psychiatrists don't just say, “This is not my area”, but instead acknowledge that for many people spirituality can be of great help.

As a group we discussed spirituality at length. We all believed there could be more compassion and care and respect shown in our mental health services.

“I have begun to experience areas of spirituality that have given me great comfort and confidence.”

We acknowledge spirituality can be a difficult area for some people. We think a distinction should be made between spirituality and religiosity or religious fixation - two quite different things, one being part of something greater than yourself the other thinking (sometimes!) that it's your mission to save the world or that you're Jesus!

“For me, if I go too deep into spirituality I can become unwell; I have learned I need to stay away from it.”

One person explains how he has had problems with religiosity, but great support from spirituality.

“At one time when I was high and thought I was Jesus. This is not unusual for the psychotic and is connected with a belief system. E.g. Christianity. For me Spirituality is a bigger concept. It has something to do with reaching a stage of contentment, of feeling integrated, of not feeling I need to prove myself...”

For all of us it emphasises the need for psychiatrists to look at all aspects of one's life and what does that person need in order to achieve a fulfilling life.

“What I needed was a skilled worker who could work with me on achieving my goals. I decide what are my priorities, and a skilled worker can help me to identify and work on goals.”

We have found the need for interventions other than medication to be important in recovery. It may have been psychotherapy, or just having someone empathic who really listens. It was often about getting back to education or getting back to work. It was often the support and love of family/friends that made a difference.

“I have been very lucky in the family I have. Though I alienated myself from some family members while unwell on previous occasions as I felt they were interfering in my life, they were only involving themselves because they were concerned about me and since I took responsibility for my recovery, relationships have vastly improved and we now interact on a far healthier level. Undoubtedly they have played a major part in my wellness.”

Educate service users on what has worked for others. Also, encourage users to make use of wellness programmes and peer support, such as SHINE, GROW, AWARE, and online programmes like Mary Ellen Copeland Wellness Recovery Action Plan (WRAP). Peer support, within the hospital, and outside is a great value in helping the person take ownership of the problem. Peer support should be available in every mental health service.

For most of us, medication has provided benefit, and we request that there is more discussion about medication. We would also request that other treatments be discussed more.

Medication side effects should be explained more. Some of us have experienced distressing side effects that were brushed aside as trivial when we discussed them with psychiatrists. We are the ones who experience them and we believe that more attention should be paid to this area, especially in light of what is now known about how drug companies have minimised iatrogenic harm associated with medication. What can be done to counter act side effects? This may require lifestyle changes - such as change to diet, more exercise, regular medical check up's and dental care. Detailed explanation on the evidence for all of this needs to be explained.

A clear explanation of how the value of a healthy lifestyle, including using the minimum effective dose of medication, and the medication that has the least side effects for that particular person, is important. We need good information on nutrition. We need information on physical wellbeing and how that can improve mental health.

“A simple statement like, if you sleep well, eat well and exercise regularly, you will recover better.”

“A great phrase used by Father in my own mental health struggles was the Latin phrase - mens sane in corpore sano....a healthy body and a healthy mind.”

Risk assessment should be made of potential benefits and risk of short or longer term effects of medication, and the information should be passed on. A clear explanation of what the medication does, both good and bad, what can happen if we stay on it, or what is likely to happen if we stopped taking it.

“I was not told in the beginning that Lithium could affect your kidneys. I was on it years when a doctor told me there were really good odds that I could stay well if I reduced it very slowly. I wanted to take those odds. Every time I discussed stopping medication with my psychiatrist he managed to convince me to stay on it. Eventually I came off it very slowly, but only told him after I stopped it, because I knew he would not agree. I have stayed well without it. ”

Weight gain with medication needs to be acknowledged and dealt with from the start. Sexual side effects from medication are another area that needs to be discussed openly. Some of us have experienced considerable loss of libido on medication. The difficulties and sensitivities associated with this need to be acknowledged and discussed.

“I have been really well for years on medication. I have had to weigh up the benefits from the side effects.”

Therapies other than medication need to be discussed more. Yoga and mindfulness has been a benefit to many of us.

“Finding some means to look at life in a more positive way, not to be worrying about the future, or eating ourselves up about the past. To learn to live in the day, has helped.”

Cognitive Behavioural Therapy to help us focus on our experiences and to help us organise our lives are helpful. Many of us have developed our own strategies to help us cope. The following conversation took place at one of our meetings.

“When you're unwell sometimes, people seem to be reflecting back to you your innermost thoughts in what they say to you or say within your earshot. I experienced this and it terrified me - I felt exposed and naked to their judgement. However, after a period of time I rationalised this by telling myself that this was the collective unconscious (Jung) at work and people didn't really know that they were referring to me when they made their comments. In this way my terror abated as I felt clothed in a cloak of anonymity once again. Maybe it's a delusion to cope with a delusion but it worked for me!”

“I get that sometimes that I think other people know what I am thinking, when I do I make sure to think of thoughts that will entertain others, this takes away the distress for me.”

The psychiatrists will wonder why we don't share these nuggets with them. We know extra medication will probably take away these symptoms, but we would prefer to take control over them ourselves, rather than increase medication. Using groups to discuss coping strategies for managing symptoms has helped.

For some of us it has been more in depth psychotherapy that has helped.

“In my experience and having a diagnosis of Schizophrenia, the psychiatrists have been very reluctant for me to attend “psychotherapy” but have recommended the safer option of “CBT”, I think that this is quite wrong, the psychiatrist should have enough trust in me to recommend psychotherapy as an option - I also think it should be my decision. In fact, with my GP's knowledge and against my psychiatrist's opinion I have successfully attended psychotherapy sessions and it had great benefit without triggering symptoms.”

Bringing the reader back to our analogy of the pothole, we wish to develop strategies to help us deal with any problems we have, and also strategies to make sure we can take ownership of our problem, believe in recovery, and make the adjustments necessary to make sure we can negotiate life's potholes.

Conclusion

We are aware there are many inconsistencies in this paper, to us this is understandable, Recovery is such an individual experience. We hope the paper has given you food for thought and will finish with a quotation from one of us, which further emphasises how individual Recovery is.

“The term ‘Recovery’ is, for me, a misleading one in mental health parlance as it implies returning from illness to a former state of being. A better term, to my mind, is the one of ‘discovery’ as it encapsulates both the retrieval of parts of one’s pre-illness coping skills and the mysterious coalescence of past and present experience to fashion a new being which can bear to face ‘the slings and arrows of outrageous fortune’. One cannot return to a former ‘self’ as one is literally ‘transmogrified’ by a breakdown whether one likes it or not into someone different, someone marked for good or ill by their experience of illness. It has often been said that recovery is a journey and not a destination, again the term ‘discovery’ fits this scenario better as one is continually learning about oneself as one goes down the road of life. Recovery, for me, is the discovery of an acceptable and accepting way of life after or during mental illness.”