



**College of Psychiatrists
of Ireland**

Wisdom • Learning • Compassion

REFOCUS CPsychI

Who cares?

Listening to the needs and experiences of carers of people with mental illness

**Prepared by carers' subgroup of REFOCUS CPsychI
with a foreword by Dr Anne Jeffers, Director External Affairs & Policy
2013**

Foreword by Dr Anne Jeffers, CPsychl Director, External Affairs & Policy

Let us start the conversation....

Any psychiatrist who is actively working with the College of Psychiatrists will tell you how the work is hugely fulfilling and greatly enhances your day to day practice. This has been my experience over the last two years, and one of the groups from which I have learned most, and from which I hope you can also learn is REFOCUS. REFOCUS, (Recovery Experience Forum of Carers and Users of Services) is made up of 10 service users and 10 family members, who have given of their time to work with the College in improving training of psychiatrists, and in identifying ways to improve our mental health services. Over the last year, through a series of meetings, REFOCUS has debated these issues, and a subgroup has written this paper, looking specifically at the role of the carer. College faculties and Council have had an opportunity to advise and comment on the paper, but the content of the paper is solely the responsibility of service users and carers of people who have used the service. Council members have welcomed the paper as a means of facilitating more dialogue between College members and both users of their services and their family members.

In introducing the paper, I will address some of the issues which have arisen in the REFOCUS meetings over the past year. At our first meeting of REFOCUS, many carers spoke of how they would do whatever was required to help their loved one, and they found it so difficult to understand how their help was not used. On the one hand, they felt cut out of their loved one's care, and on the other hand, they were expected to be ready to provide the care and support without adequate information to do so.

This paper has been written in order to address this situation and to use some practical examples of how we can all bring about change. The paper has used individual experiences to identify a number of areas where the attitude and behaviour of psychiatrists can improve the service which individuals receive. The paper looks at interventions which will improve outcomes for both the service user and for the carer.

Throughout our REFOCUS meetings family members have acknowledged how distressing the experience of having a loved one with a mental illness can be. Many speak of feeling angry, and when anger occurs they want it validated, listened to and acted upon, as appropriate. They recognise that some of the anger is a natural response to the unfairness of illness, and if this is the case, they need help to see it as such and be supported with it. Some of the anger will be justified anger at shortcomings even in the best of services. These shortcomings, almost always, come down to poor communication, and the majority of the recommendations in this paper are about improving communication.

Within REFOCUS, it is clear that service users view their illnesses quite differently from the carers, and it has been extremely helpful that service users have contributed to this paper. REFOCUS has two more papers, which will be available later in the year, each on Recovery, one written from the service users' perspective and the other from the carer's perspective.

Many College members, on reading this paper will be reassured that they are doing what is recommended, and may even question how a service could be delivered without following these recommendations. Others may feel that individual circumstances vary so much, it will not always be possible to follow the recommendations, and others may not agree with the recommendations made. However, I suggest you use the paper and its contents to open up the conversation with your own patients and their family members. Use the paper to open the conversation on communication with your trainee, with the staff in the inpatient unit, and with the community team. REFOCUS welcomes any comments on the paper, and we hope this paper will widen the conversation between the REFOCUS members, and more of our College members.

Dr Anne Jeffers

Who cares?

A Paper on needs of the carers of patients with mental health problems

Prepared by carers' subgroup of REFOCUS CPsychI

2013

Introduction

The purpose of this paper is to assist and inform the CPsychI about the role and rights of carers and the contributions they can make to the education of trainee psychiatrists and the ongoing professional development of practicing psychiatrists.

As such, this paper itemises the themes identified by the carers'* subgroup of the REFOCUS forum (patients** and carers) of the College of Psychiatrists of Ireland (CPsychI) established in late 2011. The themes were collated from the personal experiences of carers and patients submitted in writing to the subgroup and from oral and other contributions.

In all, ten themes were identified. They ranged from:

- the critically important need for psychiatrists and other mental health clinicians to recognise explicitly the crucial role of carers to
- the equally significant need for the CPsychI to give formal, structured and continuing recognition to carers in the training of psychiatrists and ongoing professional development of practicing psychiatrists.

Throughout the paper there is a selection of direct quotations taken from carers' descriptions of their experiences. These appear in italics at the beginning of each theme.

Some of the themes could, arguably, be rolled up together, but for the present, each is dealt with separately. While the themes are elaborated upon and explored in what follows, this has been done in a largely impressionistic way in what is a 'first cut' at the issues.

As a consequence, with three exceptions, no references are made to the relevant literature at this stage. The exceptions are *A Vision for Change* (2006), *The National Carers' Strategy* (2012) and a recently presented analytical paper on the implementation of mental health standards and rights in Ireland by the WHO (Kelly, 2012). That paper found that only 88 out of 166 such standards and rights were implemented in Ireland. That is a figure of 48.2 per cent, barely a pass mark and certainly not a gold standard.

Of particular importance for this paper, however, was the fact that Ireland did not score at all in relation to standards and rights of carers where there were four such rights/standards. In the broader sense, it is acknowledged that a wider body of literature as regards the needs of carers exists and this, as well as further themes, if identified, can be looked at by REFOCUS in a later version of the paper.

While the paper may appear critical, it is being presented in a constructive manner. The carers' group of REFOCUS who prepared this paper are not unaware of the excellent work with regard to carers being done by consultant psychiatrist led multidisciplinary teams around the country. In fact, a specific item on the agenda for REFOCUS is to visit such areas in order to learn from best practice.

It should be noted that none of the suggestions made in the paper are put forward with the intention of undermining in any way the legal or human rights of patients. This issue is revisited at theme 5 in the paper.

1. Explicit Recognition of the Crucial Role of Carers

“Try to establish a three member management team (patient, doctor and family member) with the patient’s permission and co-operation of course.”

There needs to be explicit recognition of the critical role of carers in the triangle of patient, multidisciplinary team (especially as led and directed by the consultant psychiatrist) and the carer when dealing with the mental health issues of a patient. Traditionally in practice, this has not been the case although some acknowledgement of the need for carers to be recognised and included as a part of the care team is reflected in Chapter 3 of *A Vision for Change* and in the recent Interim Review of the Mental Health Act 2001.

The reasons for this general omission could be:

- the long standing and understandable (at least where physical illness is concerned) principle of patient confidentiality which will be addressed later in this paper and
- the pressures of time faced by consultants and other members of the multidisciplinary team, where such teams exist.

A Vision for Change and other policy documents recognise the importance of this triangular relationship for the wellbeing of, not only the patient, but also the carer(s). In these circumstances, clearly from a policy as well as a personal point of view, there are good grounds for putting such an approach into practice as the norm.

Recommendation: Appropriate inclusion of carers in the care process in whatever way possible.

Action: Meetings with next of kin/family carer should be a recognised part of management and only omitted when the patient or family member requests that it be omitted. Examples of how this might be done would begin with simple questions such as: ‘How is your loved one’s illness affecting you?’ ‘How are you coping?’ ‘How is the illness impacting on family life?’

2. Need to Acknowledge the Unique Impact of Mental Health Difficulties of a Family Member on Carers

“really important for trainees to “really” understand what the family are going through when the illness strikes e.g. shock/fear and (many other) hurdles.”

“The unseen aspect of mental illness means that it is not always acknowledged as a possibly disabling condition and it can be emotionally disabling for the family member too.”

Besides the obvious needs of the patient, the lived experience of carer members of REFOCUS and other carers illustrates the huge impact on them of mental health problems of their relatives/friends. The impact arises not just from when the person first becomes unwell but continues throughout their diagnosis, treatment and follow-up.

The impact includes:

- the often, inordinate, demands on their time
- the stress imposed and
- the assumption that they are there as a last resort or ‘default’ in the absence of State or other supports for their family member no matter what their own personal, social and psychological circumstances.

The hopelessness and heartbreak experienced by carers, particularly at the onset of an ongoing psychiatric illness, probably, cannot be fixed but the journey to be faced by such a carer can be ameliorated by the manner in which the illness is introduced at the first point of contact between the carer and the consultant. There is an old Chinese proverb: ‘The journey of 10,000 miles begins with the first step’.

Recommendation: Be conscious of the psychological impact on carers when a family member/ loved one develops a mental health problem.

Action: An assessment of need for the patient’s family member or main carer should be carried out routinely, if agreed to by all concerned.

3. Need for Provision of Information, Knowledge and Prognoses to Carers

“My ex was never in the loop and remains exceedingly bitter about this to this day.”

“At my age, I am tired of fighting the system.”

If the unique impact of mental health difficulties of relatives on carers is conceded, as it should be, then, the question arises as to the areas in which that impact is greatest.

The experience of carers, as articulated to the Refocus group, suggests that there are four areas in particular that need to be addressed. These are:

- the provision of information as to the diagnosis of the patient
- the provision of some broad knowledge about mental health problems in general, and more detailed and timely knowledge (staggered if need be) about the specific problem of the patient, in particular
- the provision of something more than a broad outline as to the likely prognosis including timescale(s) and a broad outline of what is likely to happen in the following 12 months and thereafter
- Crucially, an indication of hope to both carer and patient

The NSUE Second Opinions 2010 and 2011 also highlighted these deficiencies

To ensure implementation of these four step procedures, it should be formally recorded on the patient's file and a copy handed to the carer.

Recommendation: Provide as comprehensive information as possible to the carer re the diagnosis, prognosis and longer term outcome underpinned by hope.

Action: All patients and family members should be given written information on the person's diagnosis, and more specific written information relating to their unique situation, to include a timeframe at which plans or management can be reviewed. This information should be reviewed and, if necessary, updated at regular intervals.

4 Recognition of the Possible Enduring Nature of Mental Health Problems

“the realisation that mental illness as something which is here for life ...is the last and most difficult hurdle to face.”

“You now have a long and hard road ahead of you...(psychiatrist to mother of patient on first diagnosis).”

“I just couldn’t do/take it anymore.”

In a sense, expressing the fact that some, although not all, mental health difficulties can be of an enduring nature could be seen as part of the provision of information requirement already discussed. However, it seems to the carers who fed in their experiences that clinicians fail to recognise this point. At the very least, carers would expect that difficult messages about the illness of a loved one would be delivered in a respectful, sensitive and supportive manner.

Specifically, it is felt that the key insight and direction from clinicians in relation to enduring mental health problems should be that, although they may be long term, such illness can be *managed* to a greater or lesser degree and that there is hope. Hope is so important for carers although this must always be seen in the context of a prognosis which is as objective as possible. Hope can be manifested and operationalized through the provision, for example, of medication and appropriate social supports and the introduction of relevant models of recovery, where the patient and carer are partnered with the clinicians in the experience.

In cases of enduring mental health difficulties, carers can be faced with a long term caring role and continuous interaction with the mental health services where they are available. It is the experience of some carers that, on first diagnosis of what may turn out to be an enduring problem for a loved one they have sometimes been left in the dark, isolated and, in the absence of any alternative, advised to contact one of the relevant NGOs such as Shine or Aware. This, at best, may reflect a lack of resources and relevant and wider expertise. At worst, it could be seen as a failure of responsibility.

Recommendation: Indicate to the carer that even long term mental health problems can be managed with the relevant supports, thereby, easing the concerns of both carer and patient.

Action: All carers should be given as clear an indication of prognosis as possible, education on the illness and information regarding support groups, such as SHINE or AWARE.

5 Use / Abuse of Patient Confidentiality to Justify Lack of Communication

“This all (lack of communication with spouse) occurred despite the fact that I had no issues with patient confidentiality.”

The title of this theme is deliberately provocative as it is felt by carers that patient confidentiality can be - and sometimes is - used as an excuse not to engage in any (inevitably) time consuming and meaningful way with the carer. Of course, the principle of doctor/patient confidentiality is a sacrosanct one, not least insofar as physical illness is concerned. The grounds for this are well established - the need for absolute trust between doctor and patient. However, carers take the view that the implications of the principle as regards mental health problems can, and sometimes do, differ from physical illness. As already indicated and while it is not in any way intended to minimise the burdens ‘other’ carers carry, mental health problems of a relative or friend can impose unique pressures on their carers. It is often suggested that mental illness is a family illness and is not confined to the patient himself or herself only.

If it is accepted that the burden on carers of those with mental health problems is unique, then, other needs, in addition to those already discussed in this paper, should be addressed. In particular, the issue of confidentiality - sometimes hidden behind in order to inhibit a wider, more constructive engagement between the clinician and the carer - should be looked at very closely. There seems to be absolutely no reason for such ‘diffidence’ on the part of the clinician where the patient has given consent to his or her carer being fully informed and engaged with and the carer also wishes it.

It is accepted that, depending on circumstances and the wishes of both patient and carer, a greater or lesser level of information may be given to and/or sought from the carer. In this context, where a patient states that his/her carer is part of their difficulties, a sensitive approach to the carer should be taken in order to establish the situation.

If carers are to be fully informed, where their loved ones agree, there might very well be a need for protocols for this to be put into practice. Carers fully respect the right to privacy of patients and do not want to intrude on patient confidentiality as such. However, they do wish to support the patient and the clinician in the process of recovery and, in this context, the provision of appropriate and agreed information is crucial. In the circumstances, the protocols might investigate the possibility of ‘bounded confidentiality’, that is to say, a sample consent form would be provided to the patient which would set out areas capable of being discussed with a carer and areas which the patient might not want to be discussed. It is recognised that such a protocol would not be necessary in all, or perhaps even, the majority of cases.

It goes without saying that, when consent is withheld by the patient, as it might be for quite understandable reasons, there would be no question of a waiver of confidentiality. A difficulty arises here where the patient is too ill to give his or her own informed consent to the waiver. There are already mechanisms which deal with the issue of incapacity and these may be further developed in the forthcoming proposed ‘Assisted Decision Making / Capacity Bill’.

However, one approach might be to provide for the possibility of an ‘advance directive’ recorded on the patient file while the patient himself or herself is well, or the waiver of confidentiality might be allowed where an appropriate process is in place. The details of such a process could be further discussed.

Recommendation: Depending on circumstances, and the wishes of both patient and carer, a greater or lesser level of information may be given to and /or sought from the carer.

Action: A clear discussion on confidentiality, and how it can be managed for the particular family, needs to occur as early as possible following contact with the mental health services.

6 Importance of Continuity of Care

“we were unable to avail of any local services and in the early days of the illness particularly it would have been a really positive link to have had a community nurse calling and offering support.”

Carers have a particular difficulty with continuing care with regard to what, as has already been noted, can be an enduring illness for a loved one. This is especially the case with the outpatient system in the community mental health programmes. While other members of the multidisciplinary team - where such exists - may try to provide some continuity, the biannual rotation of registrars leads to extraordinary frustration for patients and carers as ‘case histories’ have to be recited over and over again.

The point has been put that, in rotation situations, the only knowledge the doctor concerned will have of the patient or his or her family and social circumstances will have been gleaned from ‘a few minutes’ reading of the case file prior to the consultation.

Recommendation: This is a systemic problem but where possible all avenues to minimise this should be examined.

Action: Psychiatrists can ensure that where a person has an ongoing problem, they are assigned a care coordinator from the multidisciplinary team. Out-patient clinics should only be used for a small group of patients who require medication reviews. (*A Vision for Change*)

7 Issues of Aftercare and Follow Up

“Home visits from the local mental health team were so rare that it could be said to be non-existing.”

“I would never receive a call asking ME how things were.”

“I have still not received a call from the local team.”

This theme is, in a sense, complementary to the last. While, in the public mental health system, there are aftercare services of varying adequacy (including community care and district mental health nurses), in the not for profit system, such services are largely absent. This inconsistency sometimes means that patients and their carers can fall through the cracks, although it is accepted that this difficulty covers the wider health care system.

Recommendation: Encourage all support agencies and local community care teams to implement an improved and co-ordinated system (for example, the consultant psychiatrist, nurse or other member of a community mental health team).

Action: All patients should have a copy of a care plan, with management plans clearly laid out, and which they can choose to share with family members. Carers’ needs can be part of this care plan. The key worker could be a very useful resource in the context of care continuity. The key worker and the care coordinator suggested in the action point at theme 6 could very well be the same person.

8 The Role and Importance of Support Groups and Self Help Organisations

“Support groups have many functions and benefits but having a safe, non-judgemental and confidential space to share one’s feelings and thoughts around what is, sometimes, a taboo subject is invaluable.”

Carers typically play strong roles in support groups and self help organisations for those with mental health difficulties. The fact that carers play a significant, often ‘fronting’ role in support groups should give them a right to be listened to seriously. More importantly, the role of such organisations (where required by patient and carer) can be a significant part of ‘outpatient’ care. Carers feel that this ‘resource’ is not used sufficiently by clinicians.

Recommendation: Recognise the importance of support and self help groups for both carer and patient with an explanation of how important such services can be and provide a directory of such local services.

Action: All carers and family members should be put in contact with a local support group. Where carers do not take up this option, a meeting could be arranged for the carer with the facilitator of the local support group.

9 The Need for a Formal, Robust Complaints Mechanism and Information re same

“My son was admitted back into hospital after months of battles with his team”

The need for a formal complaints system for minor and major concerns and issues that is non judgemental and transparent for all concerned was identified. Carers and patients need to be informed of the availability of this process and given direction on how to submit a complaint to the relevant person or body, should such a need arise.

In many cases, people are not aware that mechanisms of complaint exist and are available within the Mental Health Services, in the HSE and with the Mental Health Commission. As a result, carers do not know that they have such a choice.

Such a mechanism is not a tool just to ‘sound off’ but, where, either a patient or a carer, is not being given the best possible care or attention, they do have a route they can follow to complain and/or raise concerns.

Recommendation: Appropriate information should be given to carers or patients at early stage to enable them to raise any concerns they have about the care.

Action: All services should ensure the complaints procedure is clearly displayed.

10 Formal and Structured Recognition of Carers as Important Contributors in the Training of Psychiatrists

“Practical training (for trainee psychiatrists) - where agreed and possible - to spend time in family home (night and day) for a period of time to really get a feel of what home life is like.”

“other patients in the hospital complained that these were mere relatives / carers and had no right to see and delay the doctors.”

This final theme is, perhaps, the most important in the entire paper as it is the key to everything else. If carers had a specific and structured role in the professional education of trainee psychiatrists, and the ongoing professional development of practicing psychiatrists, the other themes addressed in this paper would inevitably be dealt with over time. The perspective of the carer would then be an instinctive part of future consultant psychiatrists' day to day job. However, achieving that instinctive insight will not be attained by aspiration or, indeed, overnight.

To acquire that insight will require careful planning as to the lessons carers can teach trainee and practicing consultant psychiatrists through the medium of the CPsychI training programme and CPD events. To make it credible for trainee psychiatrists, it would have to be examinable in some way. This might be seen as a very big step but it is one that carers believe needs to be taken.

Recommendation: Assess how and where the carer perspective and role could be incorporated into the postgraduate training and CPD for qualified psychiatrists.

Action: The College of Psychiatrists will discuss how the broad lived experience of members of REFOCUS can be best used in training. In particular, this could address the need for trainee psychiatrists to understand, fully and respectfully, the experience of carers in the family/home context. The College plans to include members of REFOCUS in the College examinations in autumn 2013. All induction days for trainees should include presentations from carers.

Conclusion

The themes drawn out in this 'first cut' paper are based on the lived experiences of carers of relatives with mental health problems. They may be followed at a future date by further themes and experiences.

The importance of all carers is explicitly recognised in the recently published '*National Carers' Strategy (2012)*' which has as its vision:

“Carers will be recognised and respected as key care partners. They will be supported to maintain their own health and well-being and to care with confidence. They will be empowered to participate as fully as possible in economic life.”

It will be noted that there are no qualifications to this vision statement. The '*National Carers' Strategy*' was produced on foot of a commitment in the 'Programme for Government' (6 March, 2011) to support carers and to address issues of concern. The four national goals of the Strategy are set out in the appendix and particular attention is drawn to goals 1 and 2.

The themes identified in this paper are real and genuine experiences of carers and the roll out of ongoing or novel psychiatric care programmes in Ireland should incorporate learning from the testimony.

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Moreover, more importantly and more immediately, the perspective of carers needs to be incorporated, and structured in a formal manner, into the curricula of trainee psychiatrists and ongoing CPD programmes. It is only in this way that the perspective of carers will have a transformative and enduring impact on the provision of mental health services in the country.

** For the purposes of this document, 'carers' are defined as any family member, relative or friend who is concerned about a relative/friend who may have a mental health problem. The National Carers' Strategy defines a carer as 'someone who is providing an ongoing significant level of care to a person who is in need of that care in the home due to illness or disability or frailty.*

*** The term 'patient' is used throughout this paper although it is acknowledged that 'service user', 'client', 'consumer' and 'person with a mental health problem' could also be used.*

References:

Department of Health (2006), *A Vision for Change*, Dublin.

Department of Health (2012), *The National Carers Strategy, Recognised, Supported, Empowered*, Dublin.

Kelly, B. (2012) 'Mental Health Legislation and Human Rights in Ireland: What's next?', Paper presented at Founder's Day Conference, St Patrick's University Hospital, Dublin.

Appendix

National Goals of National Carers' Strategy

1. Recognise the value and contribution of carers and promote their inclusion in decisions relating to the person they are caring for.
2. Support carers to manage their physical and emotional health and well-being.
3. Support carers to care with confidence through the provision of adequate information, training, services and supports.
4. Empower carers to participate as fully as possible in economic and social life.