

Kara and her son's story:

Difficult journey through mental health services, with little consideration for the family

Teenager develops mental illness.....

About fifteen years ago, 15-year-old Mark was brought to a hospital A&E department with a range of psychological symptoms. After some time he was diagnosed as having schizophrenia, and that this was brought on by drug abuse (Mark had been a heavy marijuana user for some time).

For his mother, Kara, the way the diagnosis was communicated was very traumatic. The only thing from the conversation she remembered was that *'he had paranoid schizophrenia'*, there was a *'75% chance of him committing suicide'* and there was *'nothing that she could do for me'*. Their first experience of medication for the condition was also distressing. This sedated him to the extent that Kara says *'the first time I brought him out he was so doped up that he was drooling and he couldn't speak. I thought that if this was the quality of life he was going to have for the rest of his life, he would be better off dead'*.

.... commencing a 15-year journey through the system

Since then, Mark's 15-year journey through the system has involved contact with a wide range of services. Kara feels that many of the encounters were not of an acceptable quality in different areas.

A&E services

Mark has needed to use A&E services on occasions over the course of his illness. They experienced a number of problematic issues during this time like the length of time waiting for access to clinicians with psychiatric qualifications, gaining hospital admission through A&E, lack of privacy in the A&E department and families left to cope with no support *'Attitudes from some registrars are poor in relation to getting a separate room away from the main area to help in maintaining the dignity of the patient. They could cause disruption while waiting as they are very unwell'*. Kara also pointed out that a *'refusal to admit patients leaves the responsibility for coping with patients behaviour with the carer, often when they have little or no knowledge of medications, for example. This is a danger to all'*.

GP services

GP services were also problematic. Initially, Mark's GP did not realise that there was a problem and Kara says *'the GP did not know enough about mental health as he said he only had 6 weeks training'*. When she rang the hospital to get him assessed for the first time she was told that *'she was an over-reacting mother'* by the hospital over the phone. Eventually she got an appointment which ended up as an involuntary admission which she had to get referral from her GP by coming to the unit and Mark was subsequently hospitalised as an in-patient for 6 months.

Psychiatric services

Once they had gained access to the psychiatric services there were also difficulties. One issue was the inconsistency between psychiatrists in terms of emphasis on medication. When Mark decided to change his psychiatrist there were different approaches to him and every time he became uncompliant it was known as a *'blip'* and no emphasis on finding out the cause of why he was not taking his medication. Kara complained about psychiatrists because *'they were more concerned about drug levels than psychiatric symptoms or behaviour'*. She was told that a *'chemical imbalance'* was the cause of Marks problems.

On another occasion, Mark went missing from an acute unit and turned up again only through his own initiative. He was not missed by staff on the Unit for 5 hours, even though he could be a suicide risk. He went missing three times in total from a semi-secure unit.

Care plans were also an issue. *'Families should be present with the patients consent, but this was not always the case'*. When a care plan is in place it could often be deficient. Continuity of care was also a problem. *'A lot of team doctors [new junior doctors on 6 month rotations] do not read up on notes prior to interviewing the patient. Discontinuous treatment, poor handover between doctors (registrars)'*.

Relapses in Mark's condition have occurred on many occasions, especially in the earlier years. Gaining access to services when needed was often a challenge, sometime requiring dramatic measures. Kara says that, on one occasion, Mark had to be made homeless before he could receive appropriate treatment – *'I had to put him into a homeless shelter to get service They gave him many life skills – they were the life saver'*.

Lack of attention to the family & failure to listen to the carer

For Kara, the biggest problem was the lack of involvement of the family or the carer in the overall plan - *'If the person is living within the family unit, they should be involved in the care plan. If they are living independently, that is a different care plan altogether'*. However, Kara also recognises some of the challenges are within the family dynamics and it may be in the best interests of the service user not to have the family involved in his/her recovery. *'If the person refuses to let the family into the care plan while living with the family, now you have a huge problem, and how to get over this is another problem'*.

Kara feels that the carer has a key role in supporting people with mental issues, but often they have no formal role and have to struggle to make their voice heard. This can become an especially difficult when the child reaches adulthood and the carer no longer has a right to obtain information on the condition or treatment of the patient. *'Patients should be made aware that they can have a carer with them in the early stages as this would facilitate communication and treatment. We live with this all of the time and we are not educated in how to recognise problems and how to deal with them'*.

Over-medication seen as a huge problem

Much of the treatment that Mark has received has been medication oriented. One of the main aims of this is to try to maintain the equilibrium of the patient by prescribing often multiple drugs at high dosage levels. One of the difficulties for Mark and Kara is that often there is a reluctance to reduce medication to a minimum, especially where there is perceived stability in the condition of the patient. They feel that Mark was over-medicated for a long time. Kara says *'at one stage he was on 7 drugs. Eventually he was being kicked out of the housing services he was receiving until his medication was changed. This took extraordinary efforts'*.

Part of the problem with drug regimens was that Mark was not always compliant in taking the prescribed dosage. This was a continuing problem for about 10 years, but Kara says that he has been much more in control of drug dosages since then.

In recent years, Mark wanted to reduce the dosage of drugs that he takes with the help of his consultant and staff, but Kara feels there can be little support with this from psychiatric services as some will say "your levels are great, and you are doing well so you are better off staying with this dosage, why rock the boat". Mark insisted he wanted to reduce dosages over time to get a better quality of life but there was some resistance at first. There is very little encouragement given for this process. *'Mark wants to get down to the least amount of drugs possible. He knew he was prepared for it. The next thing now is he wants to come down to 300 mg, and he does get support from the psychiatrist but dosages have to be discussed first with the team and then they decide to reduce the dosage or not, this should be Mark's choice as who else knows his body better than him and if he is willing to take the chance he should be encouraged to do so at safe levels'*.

The family impact

Marks's diagnosis with schizophrenia was very traumatic, not just for himself but also for his family (his parents and older sister). At the time (and subsequently) Kara took on all responsibilities and the effects of this have taken their toll. She has had difficulties coping and subsequently became depressed herself.

The recovery path*'treatment is very good when you get it'*

After a long time (as much as 10 years), Mark began to stabilise and recover from his illness. Thankfully he is now substantially in control of the condition.

Kara feels that his recovery has in part been due to Mark growing older, recognising that he needs to have medication and taking more responsibility for managing his own care. He has also been working his way through an apprenticeship, and this has helped his recovery.

More sensitive care and family support has also played a role. Kara recognises that some of Mark's treatment has been of very good quality – *'the treatment is very good, when you get it'*. She feels that the treatment process needs to be interactive to work at its best. Clinician, carer and service users should be involved – *'questions and answers are needed, you need to know what you are talking about'*. The role of nurses was also important - *'The nurses were absolutely fabulous'*.

Lessons that could be learned

Kara points to a number of lessons that could be learned from her own and Mark's experiences with the system.

Some improvements over the years...but a lot more needs to be done

Kara acknowledges that some aspects of the system had changed for the better over the years, but feels that there is still much need for improvement at all stages of the diagnosis and treatment process.

For example, she points to improvements in the design of A&E units, the strengthening of community care services in some areas at least and to the growth of the volunteer movement – *'Volunteers are useful, but more are needed and more should be allowed, especially at the initial stages. They should be involved with the Community Teams to support others in crisis as they are experts by experience. They should be giving practical information on the basic things that carers need to know'*.

More attention to the family and carers

Kara feels strongly that clinical practice could be improved through the consistent adoption of care plans that give more attention to families as well as the patient - families and carers should be involved in care plans and treatment from the beginning of treatment.... *'Education, support and knowledge of how to cope with a crisis – this should be part of a care plan, even where the patient has reached the age of 18....'* *'The patient is the primary service user, but the family unit is the 'secondary service user'.*

Kara suggests that the HSE should *'Involve the families from the start (the Open Dialogue movement in West Cork is an example). There is an evidence base for this, but some consultants won't take it on board'*.

She also feels that families need to be assessed following the diagnosis of mental illness in a family member. They have both needs and potential resources to bring to bear on the treatment process. Kara said *'the family could have been assessed, what are their needs and resources in the context of the diagnosis?'* In addition, the indispensable role of carers should be recognised, *'If every carer who has a person with a mental health problem refused to take them back into their house, what would the HSE do?'*

Better coordination and continuity of care

Kara also feels there is a need for better coordination and continuity of care for people with mental issues. 'Recovery should be to the forefront for service users and families'. The clinical care can be improved through better handover procedures between doctors. Improved community based services are also needed – *'some good practices are in existence, but are spread unevenly across catchment areas'*.

Involving users and carers in service design

For Kara, improving clinical care is not just a matter of improving clinician practice – there should also be a bigger role for services users and carers in service design. The lack of involvement of carers in this is a big issue for her. *'Service user involvement does not involve carers! They will not let any carer/family member be a backup to a services user in any of their meetings. It is very intimidating for any service user or carer to go into a meeting of professionals on their own. They do not understand the conversation or technical terms and are too intimidated to speak up for themselves'*.

Improvements needed in medication prescription and management

Kara feels that improvements could be made in the way that medications are prescribed and managed over time. She feels that *'reductions are possible.... although complete reduction of drugs in some cases is not an option, a review system on the diagnosis should be put in place every few years'*.