Personal account by a mother who is a carer

(This account was written in 1997)

I'm trying to cope with the effects that my son's mental illness has thrust upon me. I have spent nearly 5 years struggling with the professionals and bureaucracy, as well as coping with my own personal difficulties as a Carer, and it looks as if there are many more such years to come.

I want to make it clear that I am speaking entirely from personal experience and am of course aware that other families' experiences may be very different but at heart we all share the same problems.

I am a Carer.

I cared when I was a daughter - when I was a sister -

I cared when I was a wife - for better or worse.

I cared when I was a mother - for both my children.

But now I am a Carer with a capital C because my son was diagnosed as having a serious mental illness.

I want to tell you about a number of things :

- First - What happened to me
- Next - How I felt
- Then - What my reactions were
- And also - How my feelings made me hungry.

- I'll explain what I mean by hungry in a moment or two.

First, my personal story

Four and a half years ago, my husband and I were just getting used to being able to spend precious time alone together. We had met just before my children were coming into their teens. My daughter had been living for some time in a flat of her own, and my son was in his first term at university in England. Then, about 6 o'clock one evening early in November, the phone rang.

My husband was the first to realise the full impact and stigma of mental illness with that phone call. He heard the slightly incoherent voice of the warden's wife in the university hall of residence trying to explain that our son had been taken suddenly and bizarrely ill. He could hear in her tone of voice that she had come across something she'd rather not know about.

From the outset my husband has been entirely supportive and this is especially remarkable because it is his stepson who is ill, although we have both always considered the children as ours.

With no knowledge of the illness and a six hour drive away we felt devastated. We were at a loss as to what to do next. The hospital told us there was nothing we could do, but I knew I had to be with him. He was only just 18 years old and alone in a strange city.

Trying to sleep was nearly impossible for me but at 6 am the next day I drove down south. In hindsight this was almost suicidal on my part. I was in shock, I was worn out through lack of sleep and I drove alone for 6 hours with just my thoughts in total disarray.

I spent a full two weeks staying near the hospital. During the day, I was with my son in the hospital. It was a building specifically designed for the care of the mentally ill and was open plan and modern. Due to lack of staff, this was where I first experienced my role as Carer. This was the start of our being the next shift as I call it - but that's another story.

For the next two months I travelled regularly up and down the M6. I stayed with my family who were 2 hours away from the hospital and visited my son daily. During this time, although the staff were very kind they were also very busy. I was just a mother visiting.

But I wasn't just a mother visiting. I too was someone who needed attention. I didn't know what was going on. The doctors were loathe to label the illness. I wanted my son back home with me. To cut a long story short we eventually managed to get him transferred from England to a hospital nearer home in Scotland. There were delays because there were days when our son 'decided' that he was well and would be returning to university and the transfer was put on hold.

Here we were told by doctors that our son was 'no longer our son'. I just could not comprehend what was being said, yes my son did act strangely sometimes during visits but he also had 'normal' periods and he continues to be my son. This was now two months into the illness and I was still walking around in a daze. Time wasn't my own. I woke up thinking about him and spent the day thinking about him and I cried myself to sleep each night.

One Friday, a couple of months after being admitted to the local hospital, we met with his doctor, this was now usual for us because we had made quite a fuss earlier. We were told that our son was very ill and would be in hospital for many months to come. Three days later he telephoned us to say that he was coming home that weekend - permanently.

How I felt

We were stunned. No one at the hospital even had the courtesy to inform us that he was on his way home. We had no idea of why he was suddenly released (although it later dawned on us that someone wanted a bed and pulled rank on our son's doctor - there was no other conceivable explanation, although this was hotly denied). We were given no information or help on how to cope with him. No arrangements had been made for his medication or further care.

Then a light came into our darkness. A chance viewing of a TV talk show on the subject of schizophrenia introduced us to the existence of NSF (Scotland), and through that to Nikki Martin, Tayside's Dundee-based Carer's Support Officer who offered both a listening ear and invaluable support and information

Both in England and in Scotland the nursing staff themselves were sympathetic and saying that we could talk with them whenever we felt the need. All our difficulties came from dealing with the doctors and consultants.

The only diagnosis that had been offered was 'thought disorder'. It took a great deal of research to find out what this was.

When he was eventually discharged and was getting a sick line from his GP it was the GP who was honest enough to give a name to our son's disability. It was schizophrenia.

My reactions

I was in shock. I walked about in a daze for days and weeks. I cried I even cried in my sleep. I ranted and raved at the world - Why Me? I asked. I was unable to go out in the world and see other young men and women laughing and getting on with their lives whilst my son was struck down with this awful illness.

I went through a phase of blaming myself (I still get the occasional twitch of guilt). Did I eat the wrong food whilst I was pregnant? Did I bring him up correctly? Are my genes defective? Am I responsible for his illness?

I looked everywhere for a cure. When he was home on visits I gave him vitamins after reading the articles and excerpts from books, and fed him on a Gluten-free diet. I searched and researched for alternative medicines and cures.

Worst of all, it began to dawn on me that these feelings were not uniquely mine, but were shared by others who had been through similar experiences.

As the months went by, the acuteness of my feelings began to subside, although they never went away. And it was then that I began to feel hungry. Really hungry. For what you ask?

What I was hungry for

- Hungry for information
- Hungry for knowledge
- Hungry for an understanding of what this devastating illness is all about.
- Hungry above all else to find out why the system which was supposed to be caring for my son appeared to have failed so comprehensively.

So, as I said earlier, I was more or less forced into the role of Carer with a capital C, a nurse, a welfare rights officer, a social worker, and more besides and it gradually dawned on me to ask why? Why should I be doing this when there's supposed to be a whole team of professionals in place to do it?

The Community Care Act 1990 and discharge protocols existed in the law books but apparently not in reality. Professionals were running around like headless chickens, seemingly more anxious to defend themselves and their territory than to help the user and his relatives.

Information will be given if you want it or know how to go about asking for it, but it should be automatic, not once, but ongoing.

Now I want to ask a question which has been plaguing me ever since this whole wretched business started. Why do Carers get such a raw deal? Carers should be offered counselling and training - yes, training - from the moment of diagnosis. If we are to care for the user, we must know how to cope, what to do and where to go for our needs to be met. Yet why is it that all these facilities are denied to the Carers of the mentally ill, whilst they are so abundantly available in the case of physical illness:

- Counselling is there for the bereaved - I felt bereaved, I had lost my son through no choice of his or ours.
- Counselling is there for victims of serious accidents - this was a serious accident

So why not us? After all, we are as I always put it, 'the next shift'. In other words, we take over when the professionals go home.

There is plenty of information out there, but everyone seems to have to be reinventing the wheel. If the hospital does not have its own information pack it is loathe to advise of other material available. A great majority of GPs, having little contact in their surgeries with serious mental illness, are also ignorant of what information is available. Fortunately for us, our own health centre doctors are marvellous and have been very supportive. But few are so lucky.

The emotional cost to Carers is huge, one which may have a devastating impact on their own lives and personal relationships. But the financial cost becomes an even greater burden to bear. Because of the user's incapacity to work, a great majority are on Income Support and/or sickness benefit, their Carer/relative although not on benefits may well be on a low income. Trying to meet the costs of additional food, washing, heating becomes yet another problem to face for Carers on top of the very emotional turmoil.

I was so hungry for information that I attended conferences and seminars. Many, we have had to pay for. Trying to educate myself to the standard of a nurse, a welfare rights officer and a social worker without being paid and without getting the qualification at the end of it. But I did get the information and I have now collected quite a large personal library.

One thing I have noticed, time and time again at conferences and meetings where professionals attend. They are always amazed and shocked when they hear of the plight of the Carer and how Carers feel.

When a user is discharged from hospital, and they have a Care Programme in place, people who have to deal with them are given information, have been trained, the Care Manager, has details of the user's care and social needs and he or she has been trained to deal with them. When a user is discharged into the home of a relative, the relative also becomes a Care Manager in all but name, but with no training and very little knowledge.

That raises a curious question of civil liberties and confidentiality. Political correctness is one of the things which bedevils mental health issues, and all kinds of nonsense is talked about mentally ill people having 'rights' - the right to harm and endanger themselves because they don't know what they are doing, for example.

Nothing is said of the rights of the Carers, since we appear to have none at all. But we have you say, we have now been recognised by the Carers Recognition Bill, we as Carers can be assessed for our needs in our own right as Carers. But, big but, there's no money to pay for those needs

As for the matter of stigma, that's rather odd. Neither my husband nor myself felt the least bit ashamed or embarrassed at our son's illness. However, we were and still are acutely aware of the fact that most people do, not least because of the appalling irresponsible attitude of the media when dealing with the tiny minority who are violent - and then only because of the severity of their illness compounded by the inability of the professionals to manage them properly.

The sense of stigma is felt by our son, who is terrified that anyone should know about his illness. My husband spoke at the NSF (Scotland) national conference in Edinburgh last month but he had to hide behind a pseudonym when he gave his talk and when he was interviewed for Radio Scotland, not because he wanted to - he didn't - but because our son was so frightened of anyone knowing about him and afraid of being recognised whilst he lives in the community.

One of the principal reasons why the system is failing us is because of fragmentation of care being delivered by different agencies, some 'social' and some 'medical' (though how any human person can draw a valid distinction between the two in the case of mental illness defeats me). Then each part of the system has a different budget, different agendas and the interface between them that is, their ability to communicate with each other is pretty inadequate, to put it mildly.

For all these reasons, that's why both my husband and myself have become campaigners. I became a member of many national charities because I wanted information.

The Citizens Advice Bureau, Carers Support Unit comes into contact with both users and Carers who are slipping through the net of Care in the Community.

NSF (Scotland), SAMH and PAMH help to confront and challenge ill-judged and ill-informed comments about schizophrenia and allied mental illnesses as well as giving out information and support to users and Carers.

I am fortunate in having a husband who is as concerned and committed as I am, and most importantly we can - and do - talk about every aspect of the problem. Although I am talking about our son, I am fully aware that others have different situations, which can be even more isolating if they have no one to talk to, especially if it is the spouse who has fallen ill.

But there are particular challenges to overcome when getting Carers together:

- The initial challenge is getting people to share their experiences and first-hand knowledge, because of the stigma and fear of mental illness there is a need to inform and educate.
- The next challenge is to get Carers, these are relatives and friends, to realise they are not alone and need never feel isolated again.
- The next challenge is to ensure that people new to the illness receive more personal attention than those further down the line who may prefer more general information and help.
- The next challenge is to create a structure which copes with a constant stream of newcomers without putting off those who have been before.

Carers need a good relationship with staff - we don't want to complain - but because we are not informed we are forced into making a big fuss in order to get what we should be given without asking. Carers need help. We need reassurance as much as the user, not least to be assured that our relative/friend will have no reprisals because of our comments or actions. If the only way to get results is to become a nuisance, so be it, although I want to see results for all users and Carers without having anyone make a fuss or become a nuisance.

After all, we are all in the business of meeting the needs of the user at least I hope so, although there are times when I wonder at the motivations of some professionals. Our worse moments have been when others have tried to exclude us from involvement, when we who see our son far more than they do can pick up signs that his behaviour is deteriorating and the professionals choose to ignore us.

No one wants their son or wife to be locked away in hospital. Our motivation is single-handedly to get the user as well as possible, hopefully living a productive life in the community, if not, then at least a stable and physically healthy one.

That's what I'm hungry to see happen, but there's a great deal more campaigning ahead before well-co-ordinated care, involving all concerned professionals and ourselves becomes the norm rather than the exception.

(The mother of a young man diagnosed with schizophrenia)