

Chapter 4

So you love someone with a mental illness?

In Scotland, Cathy Hamilton

First experience

Many years ago I was introduced to mental illness when my husband was diagnosed with bipolar disorder (then called manic depression), although at the time I was very naïve about how this would affect me and my family.

There was very little going on to explain things or support us, and through my own lack of knowledge I reacted to this in a very negative way.

In the beginning my husband was hospitalised for a long time. This was on and off for many years, and at no time did anyone offer to explain what was happening.

I was once called into the consultant psychiatrist's office and felt I was being held to blame for my husband's mental illness. You can imagine how distraught I was, and never forgave that person. Thank goodness things have moved on since then and the individual has long since retired.

Because I found that mental illness was so unpredictable, I had to go on my own journey to educate myself and, in turn, try to explain to my family about mental illness.

I loved my husband very much (and still do), but I kept on reacting very badly to his illness. I so wanted him to be well, and just wished that someone would say a magic word or give us a magic pill and all would be well. I really struggled through this time in my life. I felt alone, stigmatised, unsupported and left very much to my own thoughts, which were at times not healthy. I was fast beginning to feel very unwell myself, and full of despair.

Problem drinking

My husband used alcohol to deal with his illness. This was obviously not good, and it caused major problems in our relationship.

Eventually, however, he decided to do something about his drinking and joined Alcoholics Anonymous (AA). I in turn joined the sister fellowship of Al-Anon, and was able, through the 12-step recovery programme, to start to understand myself and gain the tools I'd use in my own recovery.

I learned about detaching with love, and how to listen without always wanting to jump in and fix him. When he had relapses of his mental illness (my husband has never used alcohol again to this day), instead of watching, waiting and offering loads of advice, I stood back and respected his decisions.

I learned the difference between bad behaviour and mental illness. I was able to set boundaries without thinking that this was going to cause a relapse.

To say my husband was pleased with all these changes in me would be an overstatement, but eventually we started getting to a place where we respected each other.

Carers and experience

There is still learning to be done, but being part of Support In Mind Scotland for the past 14 years and managing the Tayside Carers Support Project has given me the opportunity to work with carers all the time.

This has also been a great learning curve. I am aware, as the years have gone by, of the difference in the services and how they have improved with their support for carers.

This has been a slow process, and there is still a long way to go, but the general consensus among carers is that the quality and shape of the education, support and information you receive depends on what doctor, nurse, social worker and support worker you get.

Most of the time carers like me are looking for ways to cope with their loved one's mental illness. So looking at coping skills is high on the agenda as they help to improve the relationships.

The Tayside Carers Support Project

Our service offers one-to-one support, emotional/telephone support, practical advice on coping and access to support groups. There are also social activities and we have involvement workers, making sure that carers have a voice.

We have a Tayside remit covering Dundee, Perth & Kinross and Angus. Fortunately I don't do all this by myself any more, as there are now part-time carer support workers in Perth & Kinross and Angus, plus full-time and part-time involvement workers.

Carers who want to become more involved and 'have a voice' are able to attend meetings with healthcare and social work professionals, and be considered experts themselves by virtue of their own experiences.

We run a preparation course for the carers who want to be more involved, which has proved very positive in terms of making our carers feel informed and supported.

This is a long way from my own early days in my caring role. These days I prefer to be called a 'supporter', and I have discovered that a lot of other carers prefer this term as well.

Recognising and supporting

Unfortunately, not everyone recognises themselves as a carer. They are just a mum, dad, husband or wife, sister, brother or friend – and feel it is simply part of their function to look after the people they love.

That is why it is so important to look at our own wellbeing as carers/supporters, as far too often lives are put on hold and people's own mental wellbeing becomes an issue.

We run training courses and wellbeing days, to emphasise how to try to reclaim our lives while still supporting and loving the person we care about in a more emotionally healthy way.

This is important because we cannot support someone if we become unwell ourselves.

Many carers feel guilty about taking time out. I know I did – I thought that because my husband was depressed I should not be having any fun or having a life.

This always led to conflict, because I would then become resentful towards him for not letting me having a life, but in fact it was me who was putting my own life on hold. He never once asked me to do this and I effectively became my own prisoner.

Intense situations

Because of the nature of the caring role and because we carers love the people we are caring for, it all becomes very intense, worrying and difficult to understand.

I know that the professionals who look after our loved ones do not always recognise that there is a family out there who have become emotionally involved in the illness. Carers are hurting and very often grieving for the person they knew, and in many cases will never be the same again.

Recovery for all

I am a great advocate for recovery and always feel that no matter what degree of recovery the person achieves, it is theirs, and very often hard-earned.

I also believe there is a recovery process for the carer, because they have been affected by their loved one's illness.

It is very hard sometimes for a carer to separate their life from the life of the other person (the person they care about). I have heard many carers say that if their son, daughter, husband, wife, friend is feeling okay then that makes them feel okay.

What we try and achieve through our one-to-one support, support groups and training courses is to try to get the carer to concentrate on their own life.

This hurts, because it always feels like you are leaving the person behind, but I have to say it is also very rewarding, in that it keeps us emotionally well.

Using different techniques and language in particularly difficult situations can certainly help to calm down situations and make the other person aware of changes in you.

I have personally proved this time and again with my husband. He used to say to me, 'I may be mentally ill, but I am not stupid', and he felt I always treated him as someone who could not think or feel for himself. I had to change this in order for our relationship to flourish.

I became more aware of these things as time went by, and started to feel better within myself. What was happening was that I was beginning to reclaim my life, and that could only be a good thing.

Moving on

I am so glad that I do the job I do. It has given me an opportunity to feel, see, and understand others in a similar situation.

For me, things have moved on. It is good to have a voice and be able to speak out when I feel unhappy about services, as this is the only way we can move forward.

But what about the carers who do not feel they have a voice and are feeling 'out there' and alone?

It would be great to think that they could find help within our project or other projects, so that we can pass on our experience, strength and hope with each other.

Editor's note

Cathy has since retired from her position with Support in Mind Scotland and Tayside Carers Support Project. She has assumed a new position within NHS Tayside but continues to be involved in a range of recovery initiatives including Wellness Recovery Action Planning (WRAP) Facilitation.

Key learning points

- The carer bears the brunt of the illness, yet has to educate themselves and their family and friends about the illness. This must change. Information should be offered right at the start in ways that are easy to assimilate.
- Mental illness affects all family relationships. Close family members (siblings, children, parents) will have different needs and responses but they all need help.
- It is important to try to detach the manifestations of the illness from the person.
- Carers need to be helped to learn coping skills.
- Carers and close family are all hurting and grieving. Recovery should be for all.