That’s what it’s like to be a carer

These personal accounts of being the father of a son with schizophrenia speak to the trauma, anguish and confusion associated with the experience. They also address the development over time of acceptance, strength and hope.

That’s what it’s like to be a carer

My task is to try to encapsulate what it is like to be a carer.

To impart to you the anguish, the fear, the mourning you go through and the mental fatigue you suffer. All people suffer fits of depression and anguish at some time in their lives, but this does not go away. It haunts you like a nightmare you don’t wake up from. That’s what it’s like to be a carer.

To be terrified of your own flesh and blood (scared of them, scared for them) but loving them all the same. That’s what it’s like to be a carer.

Hiding alcohol, hiding anything that could be a weapon that they could use to harm themselves or even harm you. To talk yourself hoarse in an environment that lacks logic or reason. That’s what it’s like to be a carer.

To watch a beautiful, healthy child disintegrate in front of you. Watching the effect of the mental problem along with self-abuse of alcohol and drugs.

To see a family tear itself apart; each person individually trying to handle the mental pressure-cooker environment in the best way they know to survive. To sit, telephone in hand desperately seeking help but unable to speak; the words won’t come out. That’s what it’s like to be a carer.

You surface; like a drowning man, you stick your head above water to take another breath to carry on once more only to be pushed back down again, and again, and again. You operate on automatic, going through the motions. To most, nothing appears wrong; to them you may seem a little sad but only you know that your stomach is being torn to shreds inside. That’s what it’s like to be a carer.

You seek help time and time again. This group, this psychologist, this shelter, these people, this time around and around it goes only to end up where you started. Nothing or nobody seems to be able to help. What do we need? What can reduce the trauma that we are going through?

We need trained professionals who recognise that my son does have strengths and intellect, who comprehend the difficulties he faces getting on top of his dependencies and who can work with him to overcome those difficulties.

He needs support from professionals as well as from those who love him. To work with him to help fight his disability which seems to plague our modern society. My son is not just an idle no-hoper acting weird – he is sick! And his family is suffering too, and has done so for years. Finally we need suitable accommodation options that do not leave the sufferer feeling an inferior citizen or even worse, and the carers burdened with the guilt because their child is living in such hideous places. This is what we need!

Moving on

So easily said but hard to even contemplate when you are totally consumed by the problems of caring for someone with a mental illness. When you seem to be going around in circles with this psychologist, this shelter, this group and these people – this time, moving on is not part of your mindset. You would give anything to break the cycle, to have some relief at sometime, but how? There are things you can do; small as each may be, each will add up to make a difference. The most important thing to do is to realise the person you are caring for is sick!

They are not just idle no-hopers acting weird, who hate and abuse you at times, who go through periods of behaviour where you fear them and fear what they may do to themselves. At times they are very difficult to love! You need to separate the person from the illness. You hear it said ‘Johnny or whoever used to be such a nice boy’ – they still are! The difference is they have a mental illness with symptoms that include weird behaviour and lack of motivation, just as the symptoms of asthma are shortness of breath. If they had a different illness, still loving them is not an issue. Loving them with a mental illness is not an issue either; it understands the illness.

Take time out. Have something to do for yourself, a hobby, an interest of some kind that focuses on something else other than the person you are caring for. Take time to breathe, time to gain the strength to go on. Enjoy the good times, feel and take pleasure in the sun when it comes out. It can be a long haul, often with no end in sight, so you need ways to revitalise yourself.
Learn as much as you can about the illness. Attend the group sessions that Mental Illness Fellowship Victoria and others have. Be involved as much as you can because with knowledge comes strength and you are going to need all the strength you can muster.

Men in particular struggle with the psychological demands of caring for a child with a mental illness and this I believe has something to do with our upbringing. The instinct that we as fathers must ‘fix what is wrong’ often makes things worse by placing additional pressure on the person with the mental illness. It’s almost the person with the illness’s duty to become well, and of course, they cannot no matter how hard they want to please. As a consequence the father feels beaten – a failure because he could not fix the problem. Many men drift away, focus on other things that they can have an impact on and regain their self-esteem.

Men must set themselves free from this belief – you cannot fix mental illness! You need to learn different ways to care for the person with the illness by supporting and encouraging them in whatever they want to do. By not placing impossible expectations on them which will only make it more difficult. By trying for a moment to walk in their shoes and see it as they see it. Letting them take responsibility for their own happiness; you are not solely responsible. This type of approach can be tough but will bring you closer to the person with the illness and make handling this difficult situation easier.

There are rewards if you don’t let it beat you, and they can come in many simple ways. A hug, a smile, an acknowledgment of a love between two people. They may be brief and far between but they are precious. But as the person with the mental illness gains confidence and is allowed to make the most of their abilities there will be more time to enjoy the walk in the sun.

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Useful references
Mental Health Services Website (Vic) www.health.vic.gov.au/mentalhealth
National Alliance of the Mentally Ill (NAMI) (USA) www.nami.org
Mental Health Council of Australia www.mhca.com.au
SANE Australia www.sane.org
Beyond Blue www.beyondblue.org.au

Mental Illness Fellowship of Victoria fact sheets
What can friends and family do to help a person experiencing mental illness?
Family and carer supports and services
Collaborating with professionals