



INTERVIEW WITH **ALINE BURGESS** BY **PEGGY HAILSTONE**

Stigma – A mental health carer’s story

For 26 years—almost one third of her life—Frankston resident Aline Burgess has cared for her son, Gary, who suffers schizophrenia. And while most parents look back fondly at their child’s key milestones, one of Burgess’ key recollections is that Gary was first hospitalised with a mental illness a week before his 21st birthday.

'There needs to be a public campaign, in schools and in the community,' Aline says. Not an, 'in your face campaign' [like the Traffic Accident Commission (TAC) ads], but more of a slow, subtle, breaking down of the stereotypes and discriminatory attitudes. 'An ongoing campaign so that all Australians get the message. For example, I'd like to see the film *A Beautiful Mind* on the school curriculum,' she says. 'Things like that'

There is little doubt that Aline is passionate about creating positive change for mental illness sufferers and their carers. One of her goals—and a key goal of the PCC—is more accommodation for the mentally ill. 'It is totally unacceptable that there are so many homeless people in our area and that so many of them are suffering from a mental illness.' (*Peninsula Carer Council Annual Report 2009*). A July (2009) Herald Sun article suggested some 2050 Frankston residents were on a wait list for Ministry of Housing accommodation.

Aline argues that shelter is a basic human right. 'You or I could not imagine what it would be like to *not* know where we are going to house ourself or sleep on any given night,' she rightly points out. Yet for people with a mental illness this is one of their biggest problems. And without a base such as that provided by home and through community, the problems of mental illness sufferers are exacerbated and the stigma around them is magnified. This is evident in a (2007) report¹ which analysed the experiences of over 4,000 homeless Australians that showed that 30 per cent had some form of mental illness. Of these people, 47 per cent had a pre-existing mental health issue and 53 per cent developed the illness as a result of becoming homeless. The circle is indeed vicious.

Aline argues that the media has much responsibility for perpetuating the stigma around mental illness. 'They sensationalise, and use throw away lines like "paranoid schizophrenic" and they still run with the idea

of "split personality"'. They are also extremely quick to report on murders which involve mental illness, yet mainstream society has proven to be far more violent than the mentally ill population.¹

Since 2002 SANE Australia has worked tirelessly to alleviate social myths surrounding mental illness through their StigmaWatch program. This program annually evaluates the media, assessing the balanced/unbalanced reporting of mental illness and suicide.

In line with Aline's comments, SANE's 2008/2009 finding was, 'The most extreme stigmatising media coverage ... was sensationalised news reporting, often concerning violence or the inaccurate, misleading and hurtful use of terms such as "schizophrenic"'. On a positive note, the number of stigma reports made to SANE in the same year decreased by 18 per cent, suggesting that the campaign of speaking out and standing up does make a difference.

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Now an active advocate for mental illness consumers and carers, 75-year-old Aline is a founding member of the Peninsula Carer Council (PCC) and a committee member on the Peninsula Psychiatric Services Regional Network, the Respite and Carelink Centre Mental Health Consultative Group (Southern Region), and the Steering Committee for the Victorian Government's Department of Human Services (now Department of Health) Demonstration Project.

As a long-term carer and mental health service user, Aline is well qualified to speak about stigma and mental health. As we approach the second decade of the new millennium—and as governments, state and federal, increase their mental health spend and focus—the question is, does stigma still exist?

According to Aline and eight of her Frankston carer peers the answer is a resounding yes. 'I took these questions with me to our meeting last night,' she says, 'And it was a unanimous yes to the question on stigma.'

Sadly, stigma is not just faced by mental health consumers but by their carers as well. 'A lot of the stigma comes from the mental health system,' Aline says. 'Carers are still not included in some of the treatment plans. They are not listened to, and they are not believed as much as they should be.'

Aline's own experience of stigma cuts deep. 'Twenty six years ago there was still the tail-end of the belief that schizophrenia was caused by a dominant mother.' As a secondary school Principal who worked full-time, it was a guilt Aline and her husband initially bought into and lived with for quite some time. 'We eventually researched it and came to terms with schizophrenia being a chemical imbalance.'

When asked why carers should be heard Aline draws attention to Section 120A of the *Mental Health Act Victoria* (1986). Of particular note is Clause (3) (ca) which states that if the consumer does not give consent, disclosure of information is permitted to a guardian, family member or primary carer, if

- » the information is reasonably required for the ongoing care of the person,
- » the guardian, family member or primary carer will be involved in providing that care, or
- » where a clinician decides to disclose information to family members, guardians or carers.

Yet still carers are often not informed, information is withheld, medication changes are made without consultation, and loved-ones are released from hospital or psychiatric care without carer notification.

One of the most important things for carers, Aline says, is upfront information. 'It doesn't matter how articulate, how intelligent, how educated a carer is, when you are in hospital with a loved one, or in the first stages of diagnosis, you're in a mess and you need help. You need to be listened to and there needs to be advocacy. The Peninsula Carer Council is advocating very strongly for this at the moment.'

In terms of carers coming forward, Aline agrees it is initially very difficult. They don't want their loved one identified with a mental illness and the loved one doesn't want to be identified either. Yet early intervention is essential. It leads to better long-term health outcomes for both parties. Carers can come to terms with the situation more quickly, which means they are a better support mechanism, and the mental health sufferer can get the immediate help they need.

Another significant component of breaking down the stigma for both mental illness sufferers and carers is the importance of ongoing community education. 'I think it has to be part of everybody's knowledge. It's like now everyone knows what asthma is and what the signs are. And way back when AIDS first came about we really had no idea [about AIDS] but the campaign helped people to understand.'

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ly The final advice offered by Aline on overcoming stigma in mental health reiterates a recent Australian advertising campaign. 'The thing is people see the mental illness. They don't see the person. It's not rocket science. A person is a person regardless of whether he or she is a carer or has a mental illness or anything else.'

Note: Aline and Gary have given their consent to be named in this article

¹ Homelessness in Melbourne: Confronting the Challenges, a joint project undertaken by the *Centre for Applied Social Research* at RMIT University, *HomeGround Services*, and the *Salvation Army Crisis Services*. Researched by Guy Johnson and Chris Chamberlain. Funded by the Australian Research Council and published by RMIT Publishing.