

Chronic illness: a carer's perspective

Carers cannot care without backup, nor be everything from nurse and banker to best friend

SIX YEARS AGO MY DAUGHTER Isabella, now aged 31, was diagnosed with schizophrenia after a prolonged period of bizarre behaviour.

She had many difficulties during her childhood. She was never able to relate to her peer group, to play with them or to be included in their activities. She depended on her parents and other adults for mental stimulus. An embarrassing obsession with another student led to the first of several changes of school. She received a great deal of psychotherapy from psychiatrists.

Isabella now lives at home, receives treatment from a psychiatrist, and takes medication which generally relieves her psychotic symptoms. Isabella is a loveable, charming, sensitive, articulate and intelligent young woman, but even with medication her illness can cause serious difficulty in comprehending reality, frequent obsessional behaviour, sometimes socially inappropriate behaviour, lack of motivation and bouts of irritability. Like others with schizophrenia, she may need help in making "reality checks" — distorted and confused perceptions may be kept in check by talking to people with a better grasp of what is happening. Families, friends, volunteer helpers and professionals may be of great help here.

One effect of deinstitutionalising those with mental illness since the 1980s has been the greater burden on families. An attempt by Isabella to live away from home with others, in a house with mental health workers present from 9 am to 5 pm on weekdays, did not work. She has underdeveloped living skills, and her illness is such that she could not live by herself — she basically depends upon family care. The challenge for the family is well summed up by E Fuller Torrey in *Surviving schizophrenia*: "Family members, especially mothers, are often asked to simultaneously be the person's case manager, psychotherapist, nurse, landlord, banker, janitor, cook, disciplinarian and best friend".¹ Families cannot be all these things, and especially they cannot be psychiatric hospitals. The physical and emotional impact on the family is very great, mostly all consuming, especially for my wife. Without intellectual stimulus and some pressure to engage in activity, Isabella lapses into prolonged inactivity, passiveness and depression. She needs company to relieve her of anxiety about changing obsessions. Occasional respite care provides some relief, but is underresourced, like many other services. Consequently, a significant number of people who are seriously affected by the illness may not cope at all, and leave home, sometimes turning to drugs, alcohol and even to prostitution and crime.

Families that try to care need substantial backups, but these are often lacking. While it was recognised that deinstitutionalisation could work only with adequate social support, the quality and range of the necessary community-based psychosocial services were seriously underestimated. Isabella has been unable to receive adequate attention from services and, like many others, has suffered from a lack of rehabilitation and recovery programs.



Professor Allan Fels, his wife Isabel Cid de Fels, and their daughters Isabella (left) and Teresa (right). Photo courtesy Vicki Jones Photography, VIC.

More programs of organised recreation and activity are needed (in Isabella's case these would include, besides occupational therapy, activities such as reading together, writing together, general education on current affairs and general knowledge), as well as vocational training, counseling, help with developing living skills, structuring the day, managing diet and physical exercise, and in obtaining part-time work. A greater range of services is also needed to manage crises which occur in the course of the illness — yet even in hospital services are limited.

Some support for families does exist through social and mental health workers. Our experience has been mixed. In some instances, we experienced problems that seemed to stem partly from a failure to adequately include the family — the long-term primary carers with the best understanding of the person and their illness — in management. At other times, we experienced demeaning and dispassionate attitudes from some mental health workers. We encountered some social workers with an attachment to inappropriate or ill judged notions of independence and personal freedom for the person with schizophrenia. This has sometimes been based on a superficial understanding of that person's circumstances, reinforced by short-term involvement caused by high rates of staff turnover. A consequence in our case has been a tendency to try to lead our daughter in a quite different direction from the one we believe she should follow. For example, she was encouraged, without consultation with us, to leave home (which she did for a time) without any understanding of the likely problems. Similarly, she was encouraged to enter personal relationships which we knew would cause her distress after a short time.

There is growing evidence that early treatment may assist in alleviating the illness, and, in view of this, it would be useful if general practitioners could ensure its early diagnosis. However, inadequate attention is often paid to the early

signs and symptoms, and to the concerns of relatives, which leaves families feeling let down. Yet, there are already many other demands on our hard-pressed GPs. It will require higher prioritisation of schizophrenia by the public, by governments and by the medical profession if the illness is to secure more attention. An even harder ask is that school teachers and counsellors watch for early signs of schizophrenia. Often, they are the first to notice that something is seriously amiss, but are not trained to recognise what it is.

While satisfied with Isabella's current psychiatric care, we are disappointed that previous specialists resisted our suggestions that Isabella might have schizophrenia (given a family history of the illness) and that continuous psychotherapy from age 13 to 25 years was unproductive. It would be interesting to gather hard evidence on the outcomes of such therapy.

Schizophrenia has been stigmatised in society, a situation which we should all try to overcome. This is why we agreed to airing the issue on ABC TV's *Australian story* (www.abc.net.au/austory/transcripts/s659714.htm). Occasionally, the term schizophrenia is avoided and replaced with euphemisms such as "developmental arrest mental illness".

I do not agree; the condition should not be disguised, and the stigma associated with it should be addressed directly. It should be named in the same way that we name diabetes or asthma.

Schizophrenia does not seem to receive the priority it needs from our public health system. Australia spends less of its health budget on this illness, proportionally, than other countries, according to a recent study by the economic consulting firm, Access Economics.² This is partly historical, partly because of its low priority politically, and partly because of a failure to recognise the large social payoffs from preventing the drug-related illnesses and crime for those at the serious end of the spectrum. As an illness which extends over an entire lifetime, it has enormous personal, family, social and economic ramifications.

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letter

Providing healthcare for people with chronic illness: the views of Australian GPs

Abdullah Demirkol,* Jan Ritchie,† Pippa Craig,‡ on behalf of nine co-researching patients

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TO THE EDITOR: Oldroyd et al provide some revealing views of general practitioners on the many difficulties and few rewards arising from their care of chronic disease patients.¹ As co-researchers in a participatory action research inquiry, exploring how nine of us living with Type 2 diabetes can better manage our condition, we read the article with interest and wish to give our perspective, as patients, on the issues addressed.

Oldroyd et al report that many GPs describe chronic disease management as a "burden". We are only too aware of this negative response when we present with our chronic conditions. GPs are usually our first, and often only, regular contact with the healthcare system. Although we would like to rely heavily on them, we rarely find they have enough time for us. The standard consultation is barely long enough for renewal of our prescriptions. Yet, for a couple of us who have recently wanted extended assistance, the situation has been exacerbated when our GPs have resisted specialist referral, on the assumption that their care is sufficient.

The article reports the conflict felt by many GPs concerning implementation of clinical management

guidelines, many of which they felt were not feasible in their everyday practice. Again, we share the discomfort this brings when we are informed of the guidelines, yet know that they do not fit with our own personal situation. We would dearly love more collaboration and negotiation in developing workable solutions best suited to our own unique circumstances. As one of us states, "none of those clinical, scientific studies can possibly be as long, complex and complicated as real life". We believe we have accumulated a considerable amount of experience and knowledge about living with diabetes, and feel disappointed that our experience is not considered of value.

It is apparent that we share the same goals as GPs in seeking effective chronic disease management, but the different knowledge bases and perspectives of doctors and patients have not coalesced. Involvement in this current participatory inquiry has given us the confidence to speak out and to propose that, as patients, we should become legitimate members of the treatment team. We await an invitation to be part of the process in implementing initiatives.

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