editorial

Psychiatric Bulletin (2004), **28**, 313–314

MIKE SHOOTER

Partners in Care

Who cares for the carers?

> 'Professional men, they have no cares;
> whatever happens, they get theirs.'
> Ogden Nash: 'I yield to my learned brother' (1935)

Nash was wrong, of course. Psychiatry is, by definition, a caring profession; most psychiatrists, despite what press and politicians might say, care so passionately about their patients that they grind themselves into the ground in the process. But however hard we work, however much we absorb the suffering of our patients, however we are tempted to take that suffering home with us, most of us can shut the clinic door on our obligations when it all gets too much. And we do still have the compensation of being paid and appreciated for what we do.

Not so for the unpaid family carer, struggling night and day, seven days a week, to look after those they love with an uneasy mixture of duty and devotion, determination and despair. Elderly parents, bewildered by the unpredictable moods of a psychotic son, unsure whether they can cope any longer but fearful of what will happen when they are gone. A young mother with a husband who drinks heavily; a young father with a suicidally depressed wife; trying to protect the children amidst their own anxieties. The wife whose 200-mile round trips to see a mother-in-law with dementia were never part of the marital contract. Parents whose pride in the every achievement of a learning disabled child is blunted by exhaustion, who cry out for respite to repair their own relationship, but feel too guilty to take it up, even when it is available. And the fourth-form teenager, staying off school to look after her baby brother because her mother has had another breakdown, caring at the expense of her own irresponsible childhood.

These are not over-painted pictures, but a true reflection of everything I have heard at carers' conferences around the countries of the College's remit over the past few years. So true that they have almost become stereotypes and that, of course, is another way of making sure that we do not do anything about it. The cost of not doing so is huge. Recent research carried out by the Princess Royal Trust for Carers shows that carers suffer physically, mentally, socially and financially – and may become patients in their own turn if not properly supported.

In truth, we have known about the problems for decades, but have chosen to ignore them – the government because 50% of people with severe mental illness are looked after by families or friends and it saves the services millions of pounds a year; psychiatrists because to take on the load of carers' problems too would be the straw that broke the camel's back. And more than that, we have often put barriers in the way of carers doing the job properly. Take, for example, the problem of information. 'How can I look after someone properly when I don't know what I am looking after? How can I look after someone properly when I can't tell anyone what is happening?' The *cri de coeur* of a parent I talked to, who felt herself enclosed in a vicious circle of professional secrecy.

Why doesn't all this change? For many reasons, beginning with a persistent mythology that the family are part of the problem. Sometimes this is true, of course. We have moved a long way from Bateson's theory of the 'schizophrenogenic mother'; but as a child psychiatrist I know very well that my patients may be the ticket to therapy for much wider dynamics. And in adult psychiatry, we know all about the intensity of expressed emotions among family members that may make psychotic illness worse. Yet psychiatrists sometimes seem to ally themselves with patients against their families in ways that can have destructive consequences for care.

Little time may be taken to listen to what carers have to say or explain clinical and service policies. The odd 5 minutes at the end of a busy clinic is not enough; being paraded in front of the ward round is simply unacceptable, but it still happens. A 20-mile trip for family carers just as imprisoned by the patient's mental illness, geographically and financially, may be impossible. Where is the continuity of care for carers, uncertain of roles within the myriad multidisciplinary teams whose hands the patient may pass through, with no key worker for themselves to turn to in crisis, and who have to tell their story to someone different every time they come to hospital? Add to this the sometimes cultural insensitivity of staff who may be unaware of a particular community's attitudes to help, services whose information is rarely translated into any other language, and it is no wonder that carers sometimes give up trying to communicate with us at all.

https://doi.org/10.1192/pb.28.9.313 Published online by Cambridge University Press

editorial

And all this comes to a head in the confusion between information and confidentiality. We rely on good-quality information from carers about the background to our patient's illness. What was he like before it started; what triggers each episode off? What is her day-to-day behaviour like; what serious anxieties are provoked unseen by the community team visits at first hand? What are the strengths and vulnerabilities of the supportive structures at home; what changes are imminent that might have dramatic consequences for the patient's future? This should be met by good-quality information in return – about diagnosis, treatment options (side-effects as well as benefits) and prognosis; service structures, policies and personnel; what to be anxious about and what not, the care plan and the rights and roles within it.

There have to be rules about confidentiality, of course, to protect the therapeutic relationship from trespass; but the balance between the patient's rights to privacy and the carer's need for information has often become so skewed that little is said at all. Psychiatrists uncertain about the law will always err on the side of caution and government proposals for reform that seem to set greater store by the rights of the nosey neighbour than the nearest relative have only made matters worse. The powers of carers need clarifying in law, in the process of advance directives and in service policy; but they would be helped best by an acceptance from the outset that the therapeutic relationship is a three-way one between professional, patient, *and* their carer.

It is this relationship that is symbolised in this year's College campaign, 'Partners in Care', being run in conjunction with the Princess Royal Trust for Carers and including many other carer organisations. The campaign was launched in January by the Princess Royal herself, and she received an Honorary Fellowship when she spoke at our annual residential meeting in Harrogate. This year is peppered with public events organised by divisions and faculties with local branches of the Princess Royal Trust. Leaflets are already being produced for carers on key mental disorders, translated into several languages, and check-lists of questions for patients to ask their mental health team, carers to ask the team, and the team to expect to answer. Information all the way!

Above all, we seek to change attitudes, and attitudes set in early. From next year, there will be an obligation to use patients and carers in the training of all psychiatrists, reinforced by their representation on training scheme inspection visits. Everyone will benefit by listening to their experience. As someone who is a psychiatrist, has been a carer and continues to be cared for superbly in my own recurrent depressions, I know just how important that is from every point of view.

Mike Shooter President, Royal College of Psychiatrists

https://doi.org/10.1192/pb.28.9.313 Published online by Cambridge University Press