

“Why do relatives worry?”

Plenary address to the Relatives and Residents Association conference “Will they look after her?” London, 16 July 2008

Good morning

I feel privileged to have the opportunity of sharing my thinking with you on this important topic. In pulling together the thinking for this presentation I have drawn extensively on the experiences of people who have called the R&RA over the past years. Time moves on, but the themes remain constant.

Maybe it's natural?

Relatives do worry about the health and well being of their loved ones living in care homes, no matter how good the home may be. This could be considered a natural response to the situation they find themselves in where it has become problematic, or more likely than not impossible to support that person in 'normal' housing. This may lead to guilt and a sense of failure, and so worry sets in. It may also be the case that relatives – even those who dutifully and lovingly call in and spend many hours with a spouse, or parent – perhaps every day - see less of the resident than before the move took place.

Public image

Many people who've never set foot in a home form their opinions on the basis of the recurrent stories of poor practice that appear in the press and feature in television and radio investigations. So, these extraordinary stories come to represent the norm, causing relatives of new and long established residents to become fretful. Care homes are viewed in some quarters – and again this may be more applicable to people who have no direct personal experience as

either a resident, relative or member of staff – as being ‘the end of the line’: failure for both the resident and their family. This may not be far away from the real feelings of many people, at least in the early days as they come to terms with their changed circumstances.

Care homes also occupy a ‘frontline’ position in the battle – or debate – about who should provide care: is it still an appropriate role for the state or are such services better provided by commercial or voluntary organisations? Once again there are many strongly held views on this subject, but this may now be nothing more than a diversion, given the prevailing situation where the changes of the last 25 years or so have left us in a position where around 80% of care homes are run by small traders and bigger companies, with the remaining 20% shared roughly evenly between public and voluntary bodies. Nowadays the public sector’s role is largely concerned with purchasing places or regulating performance of homes. The central issue for many of us now is not who owns homes, but rather how good are they at giving older people a decent quality of life.

The price of care

Places in care homes are seen to be expensive, though they compare very favourably against the cost of staying in even a budget hotel on a ‘bed only’ basis. However, people’s opinions about the relative cost are perhaps affected by the belief that there is something unseemly or unacceptable about profiting from people’s need for care, leading families to question whether they are getting value for money – even when it’s not their own money that is being spent. But all this creates a climate in which it is easy to find things to worry about – and finding additional money to meet the cost of, for example

foot care can provoke strong feelings and yet more worry – can we afford to pay for the service? Can she afford to go without it? And just what is included in the fees that are being paid?

There's every reason to worry

I began by suggesting that it may be quite natural to worry, and if we look at who moves into a care home this is confirmed by the frailty of residents.

Research tells us that more than half the people moving into a care home do so after a period of hospitalisation, and falls are the principal reason for up to 40% of admissions. Today's residents are older, frailer, and more dependent than in past times and are often arriving at a later stage in their life. Many need a lot of care and attention to their complex health needs.

Estimates vary as to the numbers of people living in care homes with some form of dementia – but it is reasonable to think in terms of more than 60% of residents having some kind of impairment to their functioning – memory loss, confusion and various kinds of dementia - many of them very severely effected, leading to worries about their safety and capacity to communicate their needs and wishes across a wide range of issues.

Sources of worry

Many of the people who call the association's helpline describe themselves as frustrated or angry at being left out of the loop: uninformed, under-informed, or misinformed by a range of professionals with whom they are in contact as a result of their links to a care home resident. They stress that they are still related, still care and don't want to be kept in the dark about critical issues or even small changes in the resident's situation. This unfortunate state of affairs may be further compounded by the responses of some professionals whom

they deal with and we have heard stories of GPs who are uncooperative or disinterested to the extent that they could be accused of being neglectful of their duties. This really isn't good enough and we must challenge such abysmal behaviour. Communications are sometimes poor – with simple requests going unanswered, or the questioner being slapped down for daring to make an enquiry. The confidentiality card may be played as a way of ignoring people but there is some evidence to suggest that this 'principle' is invoked unnecessarily – as a synonym for secrecy or privacy.

Relatives seek help from us to have a voice and to be heard – these are concepts that are promoted vigorously in many other areas of social and welfare policy, but nothing like so clearly or frequently where residents' families are concerned.

This is where we came in

The Relatives and Residents Association was founded in the early 90s for precisely this reason so that relatives could assume a fuller role and become partners in care, rather than rivals to the professional staff who undertake the bulk of the caring activities. We want to overcome the 'us and them' atmosphere that can take hold, pitting staff against 'troublesome' people. Of course there are conflicts of interest between residents and various members of their family, and between professionals and lay people – some staff report problems managing families' demands to restrict residents' freedom, ostensibly to keep them safe, and experience considerable difficulty in demonstrating that their careful professional judgement is well founded and will deliver positive improvements or a better quality of life. Put crudely, if staff followed families' instincts it's likely that more people would be locked up

within the care system than in our already over crowded prisons! Locking up, strapping in and closely observing are all called for as being ways of keeping residents safe – so this debate is not a one-way street where relatives are always on the side of the angels, with unhelpful care staff failing to fulfil their caring obligations. And sometimes relatives may exacerbate difficulties by insensitivity or bloody mindedness, or exaggerate them in order to gain attention from others like the R&RA.

Meeting the standards

But worries don't only arise from the problems people have getting along with one another, struggling to treat each other respectfully and to recognise the real and imagined concerns they have about the health and well being of a frail older person. There is also some hard evidence drawn from the data supplied by the Commission for Social Care Inspection about the performance of homes. This year the annual state of social care report described the raw deal that so many self funders get from social services departments keen to reduce the pressures on their staff and services by diverting people away from the assessment process – simply because they have sufficient financial resources to meet the cost of their care. But buried in the report you'll find that there are still very substantial gaps in performance, despite improvements over the five year period since the National Minimum Standards were introduced with one in three homes failing to meet the standards either in relation to care planning or the administration of medicines.

These are fundamental issues. Care planning is about demonstrating that the home understands and has agreed the resident's needs and the steps that will be taken to meet them; while dealing with drugs is vital for health - and

safety. There have been improvements in these and other standards but the commission has conceded that improvement has stalled. That's why we continue to campaign for strengthening inspection with a return to annual inspections rather than self-assessment by homes' owners.

Medication matters loom large in the association's casebook, with callers seeking advice and support to challenge practices that they believe to be adversely affecting their relative, and these stories have been borne out by much of the evidence received by the All Party Parliamentary Group on Dementia during the course of its inquiry into the use of anti-psychotic drugs.

Meeting people's aspirations

Put simply they want the best for their loved ones. They want services that will help to maintain individuality, that sustain links with trusted services and individuals – very telling in the field of health care – and as I've said before they want to be informed and involved wherever possible in decisions.

Not too much to ask?

In the year when we are celebrating the 60th anniversary of the NHS it seems worth reminding ourselves of the commitment to health care services “free at the point of use”, more recently described by the present prime minister as a “moral right” for citizens of the UK. The idea of a ‘postcode lottery’ is rolled out too frequently in my opinion and doesn't help us to understand the complexity - or simplicity - of the problems facing us as we meet here today to discuss health and well being in care homes. There may be different policies and resources between one part of the country and another, but equally there are plenty of examples – and I'm sure we will hear about more of them during the course of today – of homes in the same district with vastly differing

approaches to the same operational issues and problems. Postcodes and lotteries are not the issue here. Leadership, commitment and the number and mix of skills within the staff group are more significant.

Double discrimination?

It's sad to say that older people living in care homes could be victims of double discrimination around health care issues where 'age' and 'place' conspire together to push them out of sight and reach of everyday services that could make their lives better.

So what is to be done?

We have some ideas on topics and themes that need to be pursued and it's likely that the list will grow as the day wears on:

- Recognition and respect for family and personal relationships;
- Sharing information more openly and routinely – on medication: the options and effects; and on the range of treatments available to meet specific needs;
- Commissioners should ensure that homes they use can gain access to a comprehensive range of health services to meet the needs of their residents;
- Inspectors and commissioners should ensure that local plans for the development of health and care services reflect the needs of care home residents.

Last words

We are launching this campaign because:

1. Around 400,000 older people live in care homes – their average age is mid 80s, and rising;

2. Many residents have memory loss, confusion or dementia and need access to a range of health care services
3. No matter how much services are modernised or transformed there will be a continuing need for this kind of provision in the short, medium and longer term
4. Care homes are well placed to respond to the drive to 'personalise' services

In a period when new strategies relating to a wide range of topics are emerging increasingly frequently – today has seen the launch of one for the 'end of life' - it should not be considered outlandish or outrageous to call for action to extend the availability of health services, to reduce and ultimately to eliminate the chance of residents being unable to access health care services as freely as their contemporaries living independently in the community.

Les Bright, 16th July 2008