



Speaking up, speaking out: making a difference for individuals and communities.

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About SCCM

Somerset Community Care Matters is a new project providing specialist advice, help and casework in the field of Community Care law, the term which applies to all advice about healthcare from the NHS, social care from social services and disability rights and entitlements to care and support. It is a registered charity, established by a group of local people concerned to ensure that the county's citizens could have access to legal help to enable them to secure their right to community care services. It began operating as a project housed within Mind in Taunton and West Somerset in early 2011.

About the author

Les Bright is an independent consultant in social care www.bcdcareassociates.org , having previously worked in local government and the voluntary sector at local and national level since qualifying as a community worker in 1977. Subsequently he studied social policy at the LSE while continuing to work as a senior manager in the social services department of a shire county council. He is the author or co-author of a number of publications associated with care, support and advocacy and is a regular contributor to care sector magazines and journals.

Preamble

This paper has been prepared as part of the process of formally launching Somerset Community Care Matters (SCCM) as a service to the county's citizens.

I was very pleased to become involved in a modest way in assisting in the establishment of SCCM, back in December 2009, when I was asked to act as the independent chair of a series of meetings to consider whether there was any chance of saving something of a service previously offered by Shelter, the national campaign for the homeless, which had run out of funding. Those meetings aimed to gather support from local organisations and key individuals. The response - not least from grateful users of the service who felt that the help they had received should not be denied to others - was extremely encouraging and led to the formation of a steering group to take the ideas forward.

Introduction

So, what's so special about SCCM? Perhaps it would be better to explore the reasons why such a service is necessary, and some of the challenges that exist for people in need of community care services. In doing this I will be drawing on the wider environment of care policy and acknowledge that not all of the problems may [yet] have occurred here in Somerset – perhaps with a vigorous, knowledgeable and determined defender of citizens' rights things will be much better – but in such challenging times, with local authorities being required to save money we may not yet have seen the worst.

Before I go any further I should make clear that I am not now, nor have I ever been, a lawyer and that this paper is in no way an assessment of the legal remedies that may be pursued. I have drawn on my experiences and understanding gained over many years working in and around social care as a practitioner and then later as a manager in both local government and the voluntary sector – at local and national level. For the past 8 years I have been working as a freelance undertaking a wide range of assignments for very broad group of commissioners, some here in the West Country, which is now my home, but predominantly for national organisations who value an independent voice, or welcome the kind of scrutiny which accompanies inviting an outsider to examine a problem or give opinions on a proposal.

During the course of my work I have met many people using services, those denied a service, and others disgruntled with the service they have received. And, equally I have met many dedicated, and in some cases inspirational staff – at all levels – working for public, private and voluntary organisations involved in looking after people with community care needs. In putting this paper together I have obviously drawn on that experience without in any way breaching confidentiality or compromising my integrity. Names used in the case studies are fictitious, the situations described are not.

Community Care – 20 years of change

“Community care is a poor relation: everybody’s distant relative, but nobody’s baby.”¹

The introduction of the NHS and Community Care Act 1990, phased in over a two year period from 1991 – 93, was the beginning of a 20 year period of change - and many improvements. As with the present Health and Social Care Bill currently before parliament it was described as being the biggest shake-up of the welfare system since the inception of the modern welfare state in 1948. It would be very easy to ignore those important changes and to simply draw attention to current pressures, and some of the fallout from the budgetary difficulties which are facing the public services and knocking on into the rest of the health and care economy – causing work for organisations like SCCM. But that would be unjust and incomplete.

That Act had the effect of getting politicians and officials to consider the social care needs of adults in a different way than they had done before. At the heart of it all was a commitment to respond to people on the basis of their needs, rather than fitting them into the services available. Put simply: if an elderly person made contact with social services seeking help the onus on the assessor - generally a social worker - was to establish what the person needed, not whether they were prepared to fill up a spare place at a day centre. Alongside of this another familiar theme was also very prominent – the notion of a ‘seamless service’ was another way of expressing the hope that health and care staff and services could work closely together for the benefit of the clients and patients they each set out to serve. This wish is now expressed as the integration of health and social care services, and is presented as being a ‘win - win’, where people using services get a better response, and there is more efficient use of public funds.

Being ‘needs led’ was not easy – people began to aspire to a more personalised response, long before the rather inelegant word “Personalisation” began doing the rounds a few years ago. It is not unreasonable that every generation wants things to be better than the situation which faced those who went before them; this is neither unusual nor specific to the world of welfare. For example, how many of us who started school writing with chalk on small personal blackboards with our individual rubbers to clear off our work, or by dipping pens into inkwells, would have wanted or expected our children to face the same kind of primitive conditions – and how many of us could have predicted that computers would become standard kit in many classrooms, with electronic whiteboards taking over from teachers using chalk to write on blackboards? This may seem like a deviation from issues associated with care and support, but it is indicative of the different standards and expectations associated with welfare provision, where plant and equipment were in dire need of being replaced and where many

¹ Griffiths, R. (1988) *Community Care: Agenda for action* – Report to the Secretary of State for Social Services

buildings – hospitals, care homes and day centres in particular – had become rundown through a lack of investment.

Somerset County Council was among the first local authorities which decided to stop running care homes for older people at the beginning of the 90s. Instead a not-for-profit trust was set up to take control of them - and initially to benefit from contractual arrangements that enabled the new operators to lay long-term plans, to be better placed to gather funding to fulfil those plans and make significant improvements. In neighbouring areas the councils carried on running homes, generally without investing sufficiently to be able to improve the fabric of the buildings to meet the higher expectations we all have, for example for single rooms, en-suite facilities and continuous improvement, and eventually to meet the more demanding standards laid down by the new national inspectorate and associated National Minimum Standards established by the Care Standards Act 2000, and taking effect from 2002.

Somerset Care is now seen to be a market leader in the provision of care, especially for older people, but also as an employer that values staff – supporting and training them to become even better at their jobs, and happier in their work. There are many other organisations – private (commercial) and voluntary (not for profit) - which run good services too, but I should not dwell too long on providers of services, but rather on those who make assessments. An assessment, and the associated care plan, then leads to people gaining access to community care services to support them in their own home, to enable them to participate more fully in society, or to give them a safe and secure home suited to meeting their needs, supported by appropriately trained staff.

Alongside of this there is a need for well-informed, adequately resourced organisations employing staff and volunteers to provide information, advice and advocacy to support people in need of care and support. This is probably not the place to discuss the advisability and usefulness of introducing market economics into health and care but it is reasonable to suggest that such a system, based on transactions between ‘purchasers’ and ‘providers’, may have adverse effects on users as the two parties seek the best deal - from their perspective. As a consequence advisers have had to develop their skills and knowledge in order to assist people in challenging decisions about the way in which their needs are to be met, or any restrictions on their choice that might be attributable to economic/financial considerations rather than objective consideration of assessed care needs.

The introduction of FACS – Fair Access to Care Services – in 2003 was intended to ‘right the balance’ so that users’ needs were measured and responded to within the context of a consistent set of criteria ranging from ‘critical’ – where risk to life and limb exists – to ‘low’ – where “...inability to carry out one or two personal care or domestic routines” affects a person’s quality of life. It could be argued that this guidance to local

authorities had a positive effect, at least in the early years, but it has also acted as a barrier to services, with councils making decisions that they cannot help anyone who is judged to be 'below the bar' – with the bar being moved upwards in response to financial pressures. Two years after the introduction of FACS half of England's 152 councils provided support to people judged to have 'moderate' needs, now less than one in five councils offer such support², with a number choosing only to help those whose situation is described as 'critical'.

Needless to say the situation is not easing. Financial pressures on local authority budgets and an alarming shortage of suitable social housing stock are increasingly jeopardising the provision of support for adults with learning disabilities, according to research due to be published in the next month by healthcare intelligence provider Laing & Buisson³.

Adults with disabilities could feel encouraged by a document produced in 2005, and containing a set of overarching policy goals, with the target that,

By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life, and will be respected and included as equal members of society⁴.

At the heart of this document is the promotion of the idea of independent living, seen as enabling choice, empowerment and freedom. It recognises that the independent living agenda is cross-cutting – taking in social care, health care, housing, transport, education, employment, leisure and recreation, rather than compartmentalised issues and service needs to be dealt with by individual departments of the local or nation state. So, it will be seen that this is an even more ambitious version of the 'seamless service', or integrated approach to service provision – with all the scope for 'border disputes' that this may entail.

3 C's....

Choice and **control** are two words that have accompanied rising consumer expectations. Politicians of all stripes have encouraged us all to believe that we should have choices in all aspects of our lives – and some people have responded by suggesting that they don't want a choice, but they do want to have **confidence** – that the services they will use are well organised, properly managed, protect their dignity and promote their interests.

² These figures were reported in a survey conducted among its members by the Association of Directors of Adult Social Services in the spring of 2010.

³ *Illustrative Cost Models in Learning Disabilities Social Care Provision* and *Cost and Cost-Effectiveness Issues in Learning Disabilities Social Care Provision* are both available as free PDF downloads from the Laing & Buisson website at: www.laingbuisson.co.uk

⁴ Prime Minister's Strategy Unit (2005) *Improving the Life Chances of Disabled People*

Giving people choices around the kind of help they can have and which organisation will be involved in providing that help has proved to be fraught with difficulties for both parties. Before people can choose they need to know what the possible choices are – but the organisation offering the choice may wish to narrow it. This may be based on cost although it will be suggested that quality ‘trumps’ cost and that such restrictions as are put upon the range of choices available to an individual arises out of a concern to ensure that the user is not being exposed to sub-standard or unnecessary services that will not meet their assessed needs. This is frequently a source of dispute and is not easily resolved – even when a third party intervenes to support an unhappy person hoping to vary decisions taken by the assessor, or purchaser of care.

On the matter of confidence, users may experience problems with the way their service is provided, or with individuals involved in providing it to them and they may need assistance in getting their concerns taken seriously and acted on. Individual confidence may be affected by wider societal confidence in the performance of services, and the statutory bodies set up to inspect them. Writing this paper a short time after the television programme *Panorama* had exposed serious institutionalised cruelty towards vulnerable adults with learning difficulties, and the failure of the Care Quality Commission (CQC) to take action following a series of contacts from an experienced and credible informant has further undermined community confidence, it is clear that advocacy of the kind which can be offered by a service such as SCCM provides is needed now more as much as ever. CQC’s failure is likely to cause some local authorities and primary care trusts to consider whether they are doing all that they should to review the effectiveness of services which they commission on behalf of their local citizens. More worryingly, it may also lead to some unhelpful duplication of effort, with local authorities reacting to concerns about decreases in the number of inspections - now being referred to by the CQC as ‘site visits’ - by conducting their own ‘inspections’ to protect themselves from accusations of not knowing what is going on in services they use for their citizens - and pay for too.

.... and 3 D’s

Research carried out for the CQC’s predecessor – the Commission for Social Care Inspection (CSCI), - published in 2008 as part of the annual ‘state of social care’ report⁵, suggested that significant numbers of people – in particular those whose capital exceeds the limits and will therefore become ‘self-funders’, are “lost to the system”. They found that people looking for help might come up against a number of strategies for dampening down demand on an overstretched system. These were categorised as being one of 3 Ds – **directives** (from government or by individual local authorities) aimed at reducing the number or types of people who might qualify for help; **discretion**

⁵ Commission for Social Care Inspection (2008) *The state of social care in England, 2006 -07*

(by individual members of staff engaged in the assessment process) whereby they use their professional judgement alongside of extant policies, to determine an individual's capacity to manage their situation until a crisis is reached; and **diversion** to alternative sources of help either in the short term or for more permanent solutions, without further recourse to either staff or resources of the local authority.

For some people “signposting” - a strategy which diverts them away from becoming a client of the state - may be their preferred goal. But for others diversionary tactics may mean that they remain anxious, while their health and welfare deteriorates, and that they make poor decisions with too little information – perhaps moving to a care home when another option would have suited their needs better, or carrying on with far too little help because of the quality, quantity or utility of the information they collect from websites, directories, and voluntary or commercial providers who may promote specific services.

Web-based information - the answer?

Councils and other organisations are increasingly promoting websites as the principal source of information on their services. Indeed the Care Services Minister, in launching the Coalition government's new vision for adult social care, stressed the importance of information to enable people to exercise greater choice and control: “*Good quality, up-to-date and accessible information direct from the council, especially on websites.*”⁶ But recent research, sampling one in three councils with responsibility for adult social care revealed a worrying trend. Researchers (of whom I was one), including lay people ‘visited’ websites with the aim of identifying the steps they should take to find care for a 90 year old lady⁷. More than half of the council websites were carrying inaccurate information and others were incomplete and far from impartial. The authors said, “*Confusing, misleading and wrong: council website information about care services is letting older people down.*” It was encouraging that a number of councils asked for copies of the report in order that they could review their own performance against the recommendations made in the report. Perhaps then they won't hear this kind of comment, “*When you ring them you are put on hold and they keep telling you that you will find it quicker and easier to look at their website but it never seems to have answers to things I want.*”⁸ Of course not all those looking for information have access to computers, or feel confident in using them for such a task – and above all they miss out on the advice that would have been an integral part of a face-to-face encounter with an assessor or care manager.

⁶ Department of Health (2010) *A vision for adult social care: capable communities and active citizens*

⁷ BCD Care Associates (2011) *At the touch of a mouse: searching council websites for information on residential care for older people* available free of charge from www.bcdcareassociates.org

⁸ Private conversation with the son of a 90 year old lady who receives help at home organised by her local authority

Transforming social care

The drive to transform social care is continuing unabated despite the change of government. This can be attributed to a number of reasons, not least that there was scope for changing services in line with changing aspirations to enable users to have more choice and to exercise greater control over the services they used. But it could also be suggested that there is an appetite for wide-ranging changes as these may bring about considerable cost savings.

The introduction of Direct Payments over the past 10 years, enabling users to control the way in which money allocated for their care is spent, was a response to the growing demands of people with disabilities who wanted to break free of a what some might characterise as a 'nanny state' that told them it knew best what they wanted. Following on from this the last few years has seen the introduction of individual budgets and 'self - directed support'. This is an important development which has – when it works well – passed control over to users so that they can manage their lives more effectively, buying varying degrees of support to meet changes in their health or routines or in response to opportunities for leisure and pleasure. But the present financial pressures are leading even those who have been firm advocates of this approach to have grave concerns about the continuing viability of it when budgets available to people are being pruned drastically. Talking with advocates in a number of regions it seems that local authorities which have been managing their budgets by drawing eligibility criteria ever more tightly, are now becoming more restrictive about the services which users can buy with their personal budgets. Telling a person with mobility problems that they should not spend money on transport is tantamount to telling them that they must be confined to their home – bringing an old friend's description of community care as 'house arrest' closer to reality.

Local authorities report that they have met the target set for them by government, that 30% of people eligible for social care support should be receiving a personal budget⁹. But even such apparently good news has to be qualified with further information – that one fifth of personal budgets have a value of less than £1000 per year – or as one person told me, "*That's enough to buy around an hour and twenty minutes of home care each week.*" On the other hand 25% of users receive £10,000 or more – the challenge for agencies like SCCM will be in supporting those who may be dissatisfied to secure more help, without adversely affecting the situations of those judged to have such high levels of need as to qualify for these larger sums of money. When fewer cakes are being baked the way they are cut up may provide the only scope for responding to growing numbers of people needing help.

⁹ News release from "Think Local, Act Personal", 14 June 2011

Reforming the law

In April the Law Commission presented the Lord Chancellor with their report on plans to reform the law governing adult social care. The very first paragraph of that report indicates the scale of the task they faced:

It is now well over 60 years since the passing of the National Assistance Act 1948 which remains to this day the bedrock of adult social care. Since then, adult social care law has been the subject of countless piecemeal reforms including new Acts of Parliament and a constant stream of regulations, circulars, directions, approvals and guidance. The intervening years have also seen the implementation of the Human Rights Act 1998, devolution, the restructuring of social services departments and numerous landmark legal judgments. It is of little surprise that not only does the law perplex service users and social workers, but also the judiciary. Adult social care law, including how it relates to other legislation, has been described at various times by judges as “piecemeal ... numerous”, “exceptionally tortuous”, “labyrinthine” and as including some of the “worst drafted” subordinate legislation ever encountered.¹⁰ (Page 1)

The report has been well received and is likely to be acted on although the timescale for the changes it will bring about is less clear. It is perhaps worth quoting another extract, by way of locating SCCM’s service as important, not a luxury that cannot be afforded:

There has long been recognition by disability groups, professionals, service providers and service users of the importance of advocacy and the valuable role it can play in supporting service users and carers. Even though this issue was not addressed in our consultation paper, the need for and importance of advocacy services in adult social care was reflected in the evidence we received. Advocacy in social care refers to a particular role, distinct from advocacy in formal proceedings as understood by lawyers. The role of the advocate is to assist disabled people to speak up for themselves, or if the disabled person is unable to do so, to communicate and represent the disabled person’s needs and wishes. Advocacy is, therefore, seen as a vital component of achieving independent living and full citizenship for disabled people. (page 185)

That this paragraph highlights disabled people’s experiences, underlines the point made earlier about the introduction of Direct Payments (and then individual budgets/self directed support) as a response to pressure from disabled people. This demonstrates that individual concerns do convert into wider community concerns, which then lead to changes affecting communities of interest.

¹⁰ The Law Commission (Law Com No 326) Adult Social Care ordered by the House of Commons to be printed 10 May 2011

Paying for services

A major distinction between health and care services – no matter how closely they are integrated – is that the former is “free at the point of delivery”, while social care has always been subject to charges, based on a financial means test. Charging policy – and how that is interpreted – has been a source of confusion, anxiety and distress for many years. One of the early acts of the Labour government when elected in 1997 was to set up a Royal Commission to look into the funding of long term care. The report, published in early 1999 was ‘received’ – but then ignored. And so the problem of who should pay, and how much, has remained and led to recurrent stories of injustice and inequity appearing in national and regional newspapers, television and radio. The issue featured at the last general election when attempts at building some kind of cross-party consensus collapsed in acrimony and insults as each side accused the other of failing the population and being ready to impose swingeing new taxes to pay for the necessary changes.

The Coalition government has established a commission, under the chairmanship of a former director of the Institute of Fiscal Studies, on the funding of care and support - due to report imminently - and so it would be wrong to speculate at this stage. However, it is worth noting that services like SCCM have expended considerable time and effort supporting people in appealing against decisions on NHS Continuing Care funding, despite the establishment of clearer national guidelines, and so it may well be that even if significant changes and improvements are made there will still be a need for suitably skilled and knowledgeable advocates to support people in challenging the outcome of individual situations.

Confronting problems

The purpose of this description of the wider environmental considerations is to underline the need for organisations like SCCM to exist, to be supported and to be accepted as a vital part of the local network of services. But a dispassionate sweep across the past 20 years, highlighting the breadth and depth of changes is only half the story – it’s also important to try to capture the realities on the ground and the everyday stories of the difficulties encountered by people, often at times of high anxiety and great stress, arising from their own or a loved one’s illness, disability or bereavement. So let’s take a look at a couple of examples that provide evidence of the scale of the problems. Sometimes when such stories are presented as evidence to support the proposition that a change of policy or practice - or both - is needed they are dismissed as mere anecdote. But such dismissive language cannot disguise the fact that for the people involved life may have changed for the worse – and it didn’t have to be like that.

Access to sources of advice and support to see things through should help people to secure, restore or improve their quality of life. Vera and Mary's stories, told below, provide recent examples of the kinds of situations where such skilled and knowledgeable assistance could have made a difference (appendix 1).

In conclusion

I began this paper by stating my pleasure at having played a part in a process which led to the launch of Somerset Community Care, and I hope that this necessarily brief - and some might say highly selective – presentation of the world it operates in makes it clear what an important role it can play now and in the future. I have deliberately focused on the help SCCM can provide for individuals, but as the title suggests I believe that the presence of an effective organisation could also affect the way in which local authorities and health bodies respond to their population, maybe leading to changes to their policies and practices.

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Appendix 1 – Case studies

Vera's story: Frank looked after his wife 89 year old wife Vera as she grew more physically frail and her memory began to fade. He cooked, cleaned, chauffeured, shopped and tended the garden. She always looked 'nicely turned out', and he was happy and fulfilled as a result. Suddenly he became quite ill and was admitted to hospital where he died a few weeks later at the age of 85. In the meantime their 64 year old son had come to stay with his mother to support her in visiting her dying husband at the local hospital. In the weeks following Frank's death he realised just how much help his mother needed but didn't know what to do about it. He lived with his wife and disabled son in a big city 100 miles from his mother. This had been fine while Frank was fit, but everything changed with his death and so David contacted the local social services – to be told that they couldn't help as Vera owned her own home.

When David told me what had happened I explained the rules and the reception he should have expected and encouraged him to make contact again. This time they responded by telling him that, as his mother might be moving to David's area, Vera would become the responsibility of that authority and so they would not be getting involved. Again, I explained the system and encouraged him to make contact – third time lucky? Well, no. This time he was encouraged to make contact with a home care agency that could help him to sort out the help his mother needed – though without an assessment it is somewhat perplexing that the 'call handler' (for s/he was certainly not a trained social care assessor) could have decided that Vera's needs would be met once the care agency had been in touch. That agency is now providing a carer who calls three times a day. Things are not perfect but Vera appears to be functioning better than she had been for some time and so I suppose things are not so bad. But, as I said to David, *"It's a bit like asking a decorating contractor to come and tell you whether the house needs repainting – if he hasn't got much work on it's likely that he will quote you for a complete makeover, whether you need it or not."*

Right now things are holding up reasonably well, although predictable glitches happen such as the carer arriving after 10.00am to help Vera get up and prepare breakfast, or getting held up in the evening traffic so that she is pacing up and down in the street looking for the carer, wondering what to do as she has no fresh food and doesn't know how to operate the new microwave oven. Even a very good advocacy service might struggle to give Vera the confidence to master a new piece of domestic electrical equipment – but maybe it would have been able to assist her and her son to secure a full assessment so that they could form a view on the full range of possibilities available to them before committing to one of which she had no prior experience.

Mary's story – a 'double whammy': Mary was 68 when I met her, and ought to have been enjoying her retirement in the bungalow on the outskirts of a small town that she and her husband Roger bought eight years previously. But sometimes things don't go according to plan. Her 71-year-old husband, who was diagnosed with dementia in the autumn of 2008, began showing signs of forgetfulness some time before that. The scale of the problem became clear on a very personal level. *"One day he said, 'Who are you?' When you've been married for 48 years this comes as a huge shock."* The pace of his illness speeded up so that after a series of distressing incidents where he went missing, and his behaviour became increasingly erratic and at times aggressive, he needed to be looked after in hospital where a specialist team tried to stabilise his condition with drug therapies. *"He simply disappeared, and the police had to get involved,"* Sue explained.

Roger received exceptional care in the psychiatric ward of the local hospital and after around 4 months he was discharged to the care home where he now lives, 5 miles from the bungalow he used to share with his wife. The care home costs £500 per week but the council only pays £375, leaving a significant shortfall for Mary to find of £125 each week to maintain his place. *"I'm happy with the home – the staff seem very good – and Roger seems to be happy there. I visit him every day, sometimes for just a short time."*

Mary's mother is 90 years old and now lives in a care home 45 miles north of her daughter. She had always been fiercely independent and had been living alone for 7 years since her husband's death. She had reluctantly agreed to a little help at home, but only because she thought this would help Mary, who had to make a 90 mile round trip whenever problems cropped up. Following a period in hospital, after yet another fall, she was initially going back to her sheltered flat but then it became evident that this was too risky and so she went to a residential care home, initially for 6 weeks respite. *"She loves it there, and I feel much happier that she is being well looked after. Her social worker is putting the case to some kind of panel in the next few days and I'm hoping that they will agree a permanent place for her."*

But as with her husband's home, the council's contribution falls well short of the weekly fee and she is paying £110 each week to ensure that her Mum is looked after. Mary estimates that she has enough to see them both through the next 2 years, after which time she will have to consider downsizing her home so as to create capital to carry on with topping up. *"...but I do live cheaper than when Roger was here. I wear extra jumpers rather than having the heating on. I've cut back because I need to – not because I want to."*

She volunteers at the psychiatric ward of the hospital where Roger had been looked after before moving to the home. When she had been going there most days to visit him she had noticed that much of the clothing that had been put through tumble drier was very creased because the orderlies had too little time to iron garments. Given that her husband – like many of us – had always been very particular about his appearance she was concerned. So now, with more time on her hands, she does the ironing – for people she doesn't know, but nevertheless cares about.

It's good to see that someone who is making a very substantial financial contribution to the public purse, by topping up the council's inadequate fee level, has not let that get in the way of being an active citizen. It is now time to take her situation seriously, before she goes under emotionally, physically and financially. This will involve reminding the council that they should not set arbitrary fee levels and that Roger's (and Mary's Mum's) care needs should be uppermost in agreeing the fee to be paid to the service looking after him.

□