

Care Concerns 2009

**The key issues raised by older
people, their families and carers
with Counsel and Care's
Advice Service in 2009**

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Worries about older people who are losing or lacking the mental capacity to make decisions for themselves has become the emerging issue for Counsel and Care's advice service in 2009. Ten per cent of all calls to Counsel and Care's advice service are from families and carers concerned about whether older relatives or friends starting to lose mental capacity, are receiving the most appropriate and high quality care available in the setting of their choice.

The top five issues that older people, their families and carers contacted Counsel and Care's advice service about in 2009 show the vital role the service has to play in supporting some of the most vulnerable older people in our society. They also display the unique and complex range of advice and information that Counsel and Care deals with on a day-to-day basis.

Enquirers' other main concerns include:

-  lack of available and meaningful information and advice for older people and their families and carers, particularly for those who pay all their care costs themselves
-  difficulty in accessing the care and support system
-  difficulty in navigating the complaints process if you experience poor quality care
-  the ever-increasing costs of care and support.

The report is based on a sample of 2,746 telephone enquiries taken by Counsel and Care's Advice Service in 2009. Counsel and Care's Advice Service reaches some 250,000 older people, their families and carers a year through telephone

enquiries, website, guides and publications. Evidence has also been included in this report from a survey of local authorities in relation to care charging and eligibility criteria during 2009-10.

The emerging issue in 2009 – support for people who lack mental capacity

The seldom-heard voices of older people without mental capacity or with dementia or other mental health problems, and the concerns of their families and carers, is the emerging issue for Counsel and Care's Advice Service in 2009.

In 2008, paying for a care home was the biggest concern for older people contacting Counsel and Care's advice service on a daily basis, making up 30% of all calls¹. While this remains a key issue – still making up over 25% of all calls in 2009 – the emphasis has shifted.

Enquirers in 2009 have been extremely worried about the support (or lack of it) available to their older relatives or friends who are starting to find it difficult to manage their finances or are struggling to make decisions about their care and support by themselves.

Counsel and Care received a growing number of calls in 2009 from families and carers concerned about whether older relatives or friends, starting to lose mental capacity, are receiving the most appropriate and high quality care available in the setting of their choice.

Enquirers are worried about situations where the wishes and wants of the older person seem to be disregarded in favour of the opinions of professionals (or sometimes other family members) once the older person has been assessed

¹ (2009) Passingham, A. *Finding and financing care in hard times*, Counsel and Care, London.
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under the Mental Capacity Act Code of Practice as having lost mental capacity for all decision-making.

From April 2009, an older person who lacks capacity to consent to arrangements made for their care and/or treatment has, for the first time, legal protection under the Deprivation of Liberty Safeguards (DoLS) (an amendment to the Mental Capacity Act 2005). If, to protect them from harm, an older person can only be cared for in a way that takes away their freedom to the extent that it deprives them of liberty and this decision raises concern or dissent, the care home or hospital must request an authorisation from either the local council or the primary care trust to do this.

The aim is to make sure that older people who lack capacity are only deprived of their freedoms where there is **no** other way to care for them or provide treatment to them safely. All other potential options must be considered first and disregarded as unsuitable or unable to meet their needs before a DoLS is granted.

Where concerns have been raised about a vulnerable person, then the local council has a right to carry out a DoLS assessment in certain circumstances in line with the code of practice. However, Counsel and Care has received a growing number of calls about situations where the existence of DoLS has been used inappropriately.

Mrs M, South Wales

"I am the main carer for my husband. I had to go into hospital for an emergency operation for a heart condition. My husband moved into a care home for a period of respite care. When I had returned home and recovered I contacted my husband's social worker to let her know that he could now return home, which my husband was keen to do. However, I was informed that he could not come home as a Deprivation of Liberty Safeguards (DoLS) assessment was being carried out. My step-son had told social services that I was not able to cope and that my husband would be better supported in a care home. At this point, I contacted Counsel and Care for advice.

The Counsel and Care Advice Worker did say that where there is a breakdown in the caring role, the local council has a duty to step in and support the older person. However, at the point that I returned home, the local council adult social care team should have spoke to me about their concerns. Although they have a right to carry out a DoLS assessment if someone seems to lack capacity to make a decision, and is thought to be at harm, I should have been consulted with as the main carer.

Ultimately, my husband's council delayed in carrying out the process, which I was told should not take more than 21 days. In the end, I was able to assist my husband to return home as he wished to do so. He is now supported at home successfully by me, with help from carers and Crossroads Care."

Concerns remain that some older people lacking the mental capacity to make such a decision for themselves continue to be moved into a care home arbitrarily without first having a proper DoLS assessment carried out. Similarly, applications for such an assessment should only be made if circumstances warrant it.

Concerns have arisen that DoLS has, in some situations, been used as a way of limiting a family's ability to support the older person, especially if there has been a conflict of interest between family members. It should not be used as a discriminate threat in order to control the family's access to the older person, but rather to identify or establish legitimate concerns about the older person by the

relevant professionals and carers involved. The family should be included in such assessments where appropriate, and the whole process should not take more than 21 days.

If a better quality of care is provided that focuses on the older person's own individual needs, wants and wishes, with a greater awareness of the way the person likes to be supported and cared for, then in many cases, there should be much less need for DoLS assessments to be carried out.

Fears about complaints

Evidence from Counsel and Care's Advice Service shows that more support is especially required for older people without mental capacity, their families and carers, to raise concerns and make **complaints** about standards of care. The fear and confusion surrounding the idea of **making a formal complaint** must be removed, along with the amount of paperwork and effort involved which can actively discourage individuals from raising their concerns.

Access to independent mental capacity advocacy must be promoted and facilitated whenever possible for older people, both for those who have support from family as well as those who do not, in order to help them make the best choices about their care and support, and raise any concerns they may have.

More people paying for all their care themselves

Recognition must be made of the vulnerability of older people who are paying for their care in full, especially those with fluctuating mental capacity or dementia who have not been able to access council support or services (see **Access to the care and support system**).

Recent research has shown that since 2002, the percentage of older and disabled people paying for residential care without any financial support from their local authority has risen by a third. The number of people who are having to pay for all their care in a care home themselves has increased to 41% of all residents (155,000 in total) in 2009².

These figures come as no surprise to Counsel and Care, as the increase is reflected in the number of calls to Counsel and Care's advice service in 2009 about older people who are paying for the full cost of their care themselves.

Over 60% of all calls to Counsel and Care's advice service from people paying for care without financial support from their local authority are now concerned with how to pay for a care home. While the relative improvement in the housing market has eased the situation for self-funders trying to release assets tied up in property before they move into a care home, times still remain challenging.

Enquirers in 2009 continue to express particular concern about using large amounts of their savings and capital to pay for care, and about how the costs of care home placements seem to be ever increasing. Average weekly fees for a residential care home in England are now £479, according to Laing and Buisson,

² Statistics for the number of people estimated to have sold their homes to pay for residential care were calculated by the House of Commons library on behalf of Norman Lamb MP. They were calculated using Laing & Buisson's Care of Elderly People, UK Market Survey 2009.

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and £669 for a nursing care home³. However, the average standard rate paid by councils towards the residential care home costs of an older person with savings of under £23,000 is £402.86 per week (less the individual's contribution).

For those older people who get some financial support from their local councils towards their care home fees, the contribution that the council makes can often be unrealistically low. Of the 33 councils who responded to our survey, 26 councils use one set figure for residential care in 2009-10, with an average standard rate for residential care of £402.86 per week. These rates seem in some cases to have been costed to the last penny, for example, one council's residential rate is £328.65 per week, rather than £328 or even £330.

Lack of good quality information and advice is also a key issue. Many older people who pay for all their care in full are left completely in the dark by statutory bodies when trying to negotiate the system and make the correct choices about their future lives. In 2009, older people with savings of over £23,000 or a property have often felt forced to make choices about their future care based on incomplete information and often during times of great stress or illness. In particular, when considering making a move into a care home, all older people, their families and carers should be able to make an informed choice. This should be based on a comparison of different care homes to establish what good quality care is and also what a reasonable fee is and what can be regarded as excessive within the care home market and their local area. As consumers, so-called 'self-funding' care home residents are more vulnerable to unfair price increases as they cannot easily switch service provider and are less able to do anything to improve their situation.

³ Laing and Buisson (2009). Care of Elderly People UK Market Survey 2009, London.

Counsel and Care aims to support all older people, their families and carers, including those who are paying for all their care themselves, to access good quality care that is of good value within any community care setting, and to encourage them to raise a complaint or access independent advocacy if they have concerns.

However, 'self-funders' should not just be dependent on getting information and advice from the voluntary sector. Counsel and Care anticipates that the Local Government Ombudsman will be inundated with calls once its remit is extended to support complaints from people who pay for services. In addition, care homes need to be much more transparent and open in providing information about their fees and giving a clear written breakdown of what their costs cover. Extra emphasis must be placed on local councils as well as private care providers to ensure that older people and their families are fully supported to access good quality, advice, information and advocacy, including independent financial advice, which can be tailored to their individual situations.

Charging for care and support at home

Recent Department of Health statistics indicate that while an estimated 80,000 older people receive free personal care at home from their local council, 40,000 older people pay part of the costs and a further 50,000 older people currently pay all of the costs of their care at home⁴.

However, these 90,000 older people with the highest needs who are paying for care will all have different experiences in relation to charging for the home care they receive. The amount an older person is charged for their home care is inconsistent and remains a postcode lottery, depending very much on where the person lives in the country as to whether it is a positive or a negative outcome. Over 10% of all calls to Counsel and Care's Advice Service in 2009 were about issues related to care charging and problems with getting care at home (see **access to the care and support system** below).

In the Isle of Wight, free home care for 2,000 people aged over 80 with critical and substantial needs was introduced in April 2007 run by the council in partnership with the primary care trust.⁵ In addition, Derbyshire council does not charge for personal care services at home for older people with moderate needs and above⁶. Two councils who responded to our queries on charging confirmed that they charge according to the cost of individual providers rather than by the hour as a result of the introduction of personal budgets. So far these innovative policies have been more the exception that proves the rule, rather than an indication of the direction of travel. In our survey of councils, Counsel and Care has seen a wide range in the level of charge that local councils are willing to set

⁴ Statistics Andy Burnham, Secretary of State for Health, provided to the House of Commons on 14 December 2009 during the second reading of the Personal Care at Home Bill.

⁵ <http://www.guardian.co.uk/society/2009/oct/07/isle-of-wight-free-care>

⁶ http://www.derbyshire.gov.uk/images/Home%20Care%20booklet%20v5_tcm9-7293.pdf

for essential home care services. Some councils charge £8 an hour to older people for their care, but other councils are now choosing to charge £17 or even over £18 an hour. This rate is simply unaffordable, especially for an older person who might need a high amount of care and support per day. An older person with critical needs may well require four visits a day from two care workers to support them out of bed in the morning and assist them to wash and dress, but if they also have over £23,000 in savings, they would be required to meet the full cost of the care themselves, less a small amount per week in Attendance Allowance.

Mr M, London

"I contacted Counsel and Care for advice after the amount my council decided to charge per hour for my care increased considerably. I had a great home care worker who I had developed a good relationship with, and I didn't want to lose the support. I contacted the home care agency directly and realised that they actually charged less per hour than my council was charging. It sounded like a good idea but I asked Counsel and Care for a second opinion as I was worried if I stopped getting care directly from my local council, I would be put at a disadvantage if I then needed more care. Counsel and Care acknowledged how expensive care had got in some areas, especially if you had savings of just over £23,000 which meant that you had to pay all the costs yourself. The Advice Worker reassured me that I would still be entitled to a re-assessment by my local council at any time if my needs increased."

Just under two-thirds of the local councils who responded about this issue in our survey do set a maximum weekly rate for home care. However, 11 councils who responded still do not set a ceiling on the amount that can be paid by an older person towards their care per week, so there is no limit on the amount that they could have to pay as their needs increase. In 2008-09, the maximum weekly charge ranged from £78.50 per week to £454.78 per week. Our survey of councils in 2008-09⁷ found that the maximum amount ranged from £60 per week to £450 per week.

⁷ Counsel and Care (2008) *Care Contradictions: putting people first? The harsh reality for older people, their families and carers of increasing charges and tightening criteria*. Counsel and Care, London.
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The Coalition on Charging has found that 80% people who stopped using council care services highlighted the high cost of charging was a key reason for taking such a step⁸. The current system is clearly undermined by its propensity to hit the most vulnerable hardest, so they struggle with complex needs whilst also having to pay the most expensive care bills. One local authority highlights that ‘a further review of the charging policy is imminent to ensure that this complies with the principles of the personalisation agenda’. While this is a positive step, the same council also anticipates that ‘income from charges will continue to be maximised where possible’, surely a contradiction in terms.

The Welsh Assembly Government is taking firm steps to address the current variation in charging policies that currently also exists in Wales with a proposed unified charging policy and a universal maximum charge for care that councils will be able to charge less than what is considered reasonable, but not more⁹.

There is scope for England to take such welcome developments into account as another essential stepping stone towards the implementation of a fairer and more consistent care and support system in England.

If implemented, the Personal Care at Home Bill currently going through Parliament offers the potential for all eligible older people with critical needs to receive free ‘personal care’ at home. This is a welcome step forward. However, Counsel and Care does have real concerns that some local authorities already struggling with extremely tight budgets will cut back on care provided elsewhere in the system in order to meet these compulsory costs. Some local authorities

⁸ Coalition on Charging (2008) *Charging into poverty? Charges for care services at home and the national debate on adult care reform in England*. National Centre for Independent Living, London.

⁹ <http://www.new.wales.gov.uk/about/cabinet/cabinetstatements/2009/090629socialcare/?lang=en>

may even look to further restrict the amount of support they provide to older people with substantial and moderate needs in order to make the efficiency savings required to meet the full costs of all older people in their area with critical needs.

The forthcoming White Paper on the reform of care and support must ensure that paying for care is transparent and equitable, but most of all works to ensure a good quality of life for all those using services.

Access to the care and support system

Despite the need for more person-centred care in order to better support older people lacking mental capacity, only results from the survey of 33 English local authorities undertaken by Counsel and Care¹⁰ shows that only two of the 33 local authorities – Sunderland and Calderdale (greater low) – continue to meet all the needs of older people in its local area, including those requiring what is deemed to be a ‘low’ or ‘moderate’ amount of support. Overall, a third additional council – Darlington – also meets all four bands, according to the latest figures from the Care Quality Commission¹¹.

Access to care and support services for older people with low needs is, therefore, disregarded by all but the bravest of councils, and 19 of 33 councils responding to the survey consider an older person eligible to receive care services in their area only if they have ‘critical’ or ‘substantial’ needs. Three local authorities of the 33 respondents met the needs of only those older people with the most critical and urgent needs. Of the local authorities included in the snapshot, nine local authorities met moderate needs in 2008-09 and planned to continue to do so for

¹⁰ The data in the snapshot was gathered through Counsel and Care’s annual survey of local authority care charging and eligibility criteria for older people in 2009.

¹¹ Care Quality Commission (2009) Performance judgements for adult social care services, Care Quality Commission, London. See Appendix E of the report:
http://www.cqc.org.uk/db/documents/94717_APA.pdf

all of 2009-10. A number of councils are now meeting what they describe as 'high' moderate needs, effectively adding a fifth layer of eligibility to the cake.

The survey shows how local authority provision for lower level care services, still vital to ensuring an older person's independence and dignity are maintained and that they remain an integral part of their local community, remains limited across England.

The councils have reported a variety of additional services available to older people in their area who are not eligible against the criteria, including more effective signposting methods and partnerships with local voluntary organisations and advice services. However, the Local Government Association acknowledges that despite additional services provided by councils, 'a substantial number of people who need more than 'a little bit of help' are not getting the support they need¹².

While some councils are still holding out despite tightening budgets, Counsel and Care is concerned that this will not stay the case for long due to the extensive spending cuts anticipated in the near future. A growing demand for services in particular due to the increase in older people with depression or greater ill health as been attributed by one council as a direct result of the recession. Other councils have highlighted an increase in the number of self-funders requiring financial support at an earlier stage. This increasing demand has appeared at the same time as predicted cuts in public services.

In addition, despite the current development of new Government guidance¹³, the majority of local councils' interpretation of the Fair Access to Care Services

¹² Local Government Association (2009), *Facing facts and tomorrow's reality today: the cost of care*, LGA, London.

¹³ Department of Health (2009), *Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care Guidance on Eligibility Criteria for Adult Social Care, England 2009 (consultation stage)*.

Department of Health, London.

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criteria does not sit well with the future vision of a National Care Service where all a person's health and wellbeing needs can be met in the round using a personal budget. While the policy world has signed up to the idea of a care and support system based on achieving an individual's chosen outcomes for their life, the reality for the vast majority of older people, their families and carers continues to be restricted to the traditional view of older people as passive recipients of care services. More free support must be available to older people who may benefit from a personal budget, including those who lack capacity to make decisions for themselves.

Without a huge U-turn by the majority of councils, it seems more and more likely that only those older people with the highest dependency needs and without available support from families, will get care from their local authority. As a result, the strain will be picked up by over-stretched voluntary services or pressurised families and carers who will have step into the breach to fill the gap between the growing demand and the limited reality.

Change must come in 2010

Doing nothing is not an option for 2010. The urgency of the situation has started to sink in. The new Personal Care at Home Bill is a step on the way towards a better care and support system. But the issues highlighted from Counsel and Care's Advice Service in 2009 show that reform is urgently needed on a much wider scale.

The forthcoming White Paper on the future of care must answer the concerns of the general public. It must be clear about what care people will get and how much they and their family would be required to contribute.

Consensus on a new model of care and support, together with a clear and realistic approach as to how it will be funded must be established as a matter of urgency in order to ensure that the needs of all older people, their families and carers in England are met regardless of where they live or their supposed 'level' of entitlement.

Meantime, independent and good-quality advice, information and advocacy services remain essential to ensure that all older people, their families and carers are able to get the best care and support available when they need it. And when reform takes place, information, advice and advocacy must become an integral part of the new care and support system.



Counsel and Care is the national charity working with older people, their families and carers to get the best care and support.

We provide personalised, in-depth advice and information, which informs our research and campaigning work.



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