

**Coalition of Carers in Scotland
&
Highland Community Care Forum**

**Carers' Views on, and Experience of,
the Financial Impact of Caring
in the Rural Areas of Highland**

December 2008

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Carers' Views on, and Experience of, the Financial Impact of Caring in the Rural Areas of Highland

1. Introduction

Caring matters deeply to individuals, families and society in general. Those who provide unpaid care for relatives and friends save the public purse in Scotland an estimated £7.6 billion each year. Sustaining the ability of carers to provide the care and support they give to others is of critical importance.

Whilst health and social care issues clearly have a huge impact on carers, those related to finance, including benefits and employment are of equal importance. Many carers face financial pressures due to the additional costs of caring and from either reducing working hours, moving into lower paid work, or giving up paid work.

The main benefit for carers is Carer's Allowance which is just £50.55 a week – the lowest of its kind. To be eligible for Carer's Allowance, a carer must provide at least 35 hours of (unpaid) care to a person receiving a qualifying disability benefit. Currently, approximately 470,000 carers receive Carer's Allowance.

According to the 2007 research report 'Carers in Crisis', from Carers UK, caring has a considerable impact on a carer's income and quality of life. 79% of carers who were surveyed reported that they struggle to pay utility bills like gas, electricity, water or telephone bills.

Over of half of carers surveyed reported that they have had to cut back on food costs and heating.

In addition, 48% of carers reported that they have cut back on caring support services, such as respite care, because they cannot afford them. This raises serious concerns about the future health and wellbeing of carers and their ability to sustain their caring roles.

The Caring in Crisis report found that amongst the first things that carers cut back on when experiencing financial hardship are leisure activities and non-essential transport costs. This inevitably leads to increasing isolation and loss of support networks. This is particularly difficult for carers living in rural areas, who experience less opportunity for social contact and heightened social isolation.

This report aims to examine the financial impact of caring for carers living in remote and rural highland communities. It examines the challenges associated with living in a rural community and how combining this with a caring role can significantly impact on carers' finances and quality of life. Finally, actions are suggested that need to be taken by local and national government to address these problems.

2. Methodology

The Coalition for Carers in Scotland was granted funding from the Scottish Health Council to appoint Community Facilitators in rural areas of Scotland. Their remit was to engage carers in rural communities in influencing the development of health and social care services in their local areas, and in contributing to the national picture of the impact of national policy.

The remit in Highland for this project was

- a) to ensure that the views & experience of carers in rural parts of Highland reach the people, both at local and national level, who make decisions about meeting carers' needs
- b) to make it as easy as possible for rural carers to take part in contributing their points of view

Twenty three carers living in rural areas of Highland were recruited. This was done through contact with the staff at Highland Carers Project. Forty letters were also sent to members of the Highland Carers Network. Six people responded positively to this and a further four were recruited at an open meeting organised by the Ross-shire Community Care Forum Development Worker on Carers Rights Day.

These recruits were enthusiastic about the project believing it very important that a picture of the lives of rural carers was given, because of their perception that they are often not adequately taken account of by those who make policies and manage services.

'I have seen for myself the importance of collating information in a way which allows parents to offer opinion without fear of consequence and I hope that through these consultations rural parents and carers can become the ground swell that influences change.'

'It is too easy for Local Government to concentrate their resources on centres of population and basically ignore rural carers, who are unable to complain effectively if they are not supported.'

Those who agreed to become involved live in places well distributed across Highland. Four live in small country towns, six in villages and the others are many miles from the nearest settlement. There are six men and seventeen women.

The profile of the group is as follows:

Caring for an elderly parent	4
Caring for an adult son/daughter	2
Caring for a school age child	8

Caring for a partner	7
Caring for more than one person in household	2

All participants were telephoned initially so that the project worker could introduce herself, explain the aims and the format of the work and to find out if they would prefer to be involved by email or by telephone. Ten opted for telephone and twelve for email.

Shortly afterwards people received an email or telephone call to outline the first topic for consideration with a reply date ten days later. Those contacted by phone were offered a choice of discussing the topic there and then, or making an appointment for a further phone call once they had had time to give the subject some thought.

People were asked first of all just to give their views on the topic and then five open ended prompts were used to encourage people to expand on their thoughts:

- 1) The ways in which being a carer has affected your finances
- 2) The impacts you see this having on your family/household, especially anything that you think is more significant due to the fact that you live in a rural area
- 3) The ways in which you think the income and expenses of rural carers are more affected than those of carers who live in big centres of population, eg the cost of travel to services, the lack of choice of work opportunities that fit the hours you could be available to work
- 4) The type of action you think needs to be taken by local/central government, or other organisations, to improve the situation.
- 5) Whether you are being charged for any care service you receive, and what your views are about that.

Nineteen of the twenty three people responded.

People were encouraged to 'talk in free flow' on the topic, and then 5 prompts were used to see if people wanted to expand on their thoughts.

3. Summary of Responses

Financial Changes Due to Becoming a Carer

Loss of earnings, or earnings potential and the additional costs of caring were mentioned by almost all. The most significant additional costs were related to transport and to the need for constant heating in the home. Others included replacement and repair costs where there was extra wear and tear, for

example due to children with behaviour difficulties, specialist diets, paying for care or specialist equipment or alternative therapies.

The Impact of These Financial Changes

For most people money was an underlying cause of worry, and for some a constant struggle. People talked of careful budgeting, the need to borrow money, buying only second hand clothes, doing without what others might regard as normal, worries about the future – and suffering from others' lack of understanding about how caring can affect your way of life and budget.

Specifically Rural Issues

Transport issues were seen to be the most significant; the distances to be travelled for treatments, services, social life, activities, work opportunities; the high cost of fuel in rural areas; the need for two cars due to the lack of public transport. Fuel is not the only item that is more expensive when you do not have easy access to large supermarkets.

The lack of choice and opportunity was noted by several people, restricting the chance to work, the uptake of services and therapeutic activities and possibility of personal development with a view to improving circumstances in the future.

Action Required by Agencies

As the topic under consideration was finance many suggestions were made about ways the government could improve the income of carers, ranging from completely overhauling Carers Allowance, through paying carers the minimum wage, or that of a care worker, to mechanisms like tax credits and awarding the same concessions and grants as are available to pensioners.

The pleas for increased income reflected not just people's sense of poverty, but also a need for recognition of caring as a respected role in society.

Suggestions for easing the burden of transport and fuel costs were put forward by several other people, and there was a wide range of individual comments and suggestions relating to different aspects of life, including the need to alter the rules about earning and learning while caring, support for alternative therapies which people had found to work and the advantage of having a high profile celebrity who would speak up on behalf of carers from the basis of personal experience.

On a more local level the need for improved provision of information was highlighted, along with the need for better transport options.

4. Financial Changes Due to Becoming a Carer

There are several strong themes here. Loss of income or potential income was mentioned by all except those who were already over retirement age at the time their caring role began. Almost everyone had extra costs in their household directly related to the caring situation. Several had issues about

the benefits system, many to do with lack of information in the early stages of caring. A few others mentioned the need to be in self employment as the only way of achieving the flexibility required by their circumstances. A few mentioned that the studying they had hoped to do in order to improve their employment prospects in the future had had to be abandoned as caring left no time, money or energy to achieve this.

a) Loss of Income All who mentioned loss of income felt that if they had not been caring for a relative they could have been in full or part time work. Many had given up work altogether, losing out on salaries of, in a couple of cases, up to £50,000 per annum. Others may have gone part time or taken up work at a lower number of hours and/or wages in order to be home at the appropriate time for their caring responsibilities. And there were others who had foregone promotion in order to be able to carry on caring.

'I could have expected to be in a £20000 by now if I had not had to be a full time carer'.

'I left work just over ten years ago to care full-time. At that time I had been recently promoted, with a salary of just over £38K p.a. plus benefits including a leased Mercedes. If I had stayed in work I could reasonably expect to be earning in excess of £50K p.a. plus benefits by now. We swapped this for no income at all for the first three years, living off my partner's benefits and a small income from my savings. I now have a small occupational pension plus the derisory Carers Allowance - a fraction of what I was earning ten years ago.'

b) Extra Costs due to Caring

Almost all referred to extra costs associated with caring. The most common were:

- Travel to services, such as respite care, doctors' appointments, treatment centres, therapeutic activities

'Certainly travelling to and from medical appointments is time consuming and expensive if you live in a rural area. A doctors appointment is 68 mile round trip. The hospital and the Puffin Pool for physiotherapy is 108 miles round trip and Raigmore is 140 and on top of that we had Edinburgh Royal Infirmary. This is not only expensive in respect of diesel but also tyres and miles on the clock.'

- The need to have heating on all day because they were not out at work, but at home with an older person who was not very mobile, or perhaps with children not regularly attending school

'With my son being at home during the day the heating needs to be on, and even through the night as he often doesn't sleep for any length of time, so he and I are up sometimes for several stretches during the night'

Each of the following was mentioned by a few people:

- The unusually high replacement or repair costs for furniture, toys, clothes etc, associated with children with behaviour difficulties, some of whom would have attacks of violence or constantly be breaking things or wearing them out through repeated use/abuse.

'We need very solid furniture and sturdy toys. We're always needing to replace things like chair covers, clothes and shoes because they get damaged. And on top of that its often hard to find things that xxxx will accept, so due to his condition we're always experimenting trying to find something that he can like and won't throw aside.'

- The need for very specific activities to suit an individual situation, such as a sibling going to a young carers group, or a therapeutic activity for an autistic child, often at a considerable distance from home.
- Travelling long distances for very specific treatment, not available nearby, in some cases requiring frequent trips.
- The extra expense of fresh or specialist food bought because of trying to avoid additives or particular types of food which affected the behaviour of their children or avoided allergies
- Paying for care or aids/equipment, either because this was not being covered by Social Work (or any other agency) or because 'babysitting' is required for other children. Sometimes it was because people did not know that care was available through statutory services and might have been free.

' I pay for someone privately to keep my wife company for one morning a week. I am not being charged for or have been offered any care services'

- The need for separate activities for children in a family due to the behaviour difficulties of one (or more).

'X has lots of energy. His behaviour is better if we do lots of things that use up his energy, but my wife's health is poor and she can't cope with this all the time.'

- The need to compensate other children in the family because of the lack of attention they get due to the demands of a sibling requiring constant care or monitoring

c) Benefits Issues

There were several examples of people who could have been better off if they had known more about the benefits system earlier

'We did not know that we could claim benefits for 2/3 years and lived off of savings.'

Or if the benefits system had taken more account of the realities of rural life

'Motability became unrealistic as the annual mileage allowance is not enough to meet our needs – when we had a Motability car we had to buy another car well before our three year contract was up, because the charge for going over the permitted mileage was so high! The Motability car sat unused for at least six months!'

d) Self Employment

Flexibility was seen by most to be absolutely crucial, the ability to be able to respond at short notice to the higher likelihood of crisis that the cared for person might have whether at home, or elsewhere at the time.

'I have always had to be available for our son - he has required regular hospital treatment over the years, and would catch every sniffle or bug that was doing the rounds - his recovery taking much longer. Also I have to be his transport – to and from school, hospital, hydrotherapy, RDA, to play with friends, etc.'

Several people mentioned that being self employed was the only way to achieve this flexibility, some as an aspiration and others as the solution to their particular situation.

'Who would want to employ me! My old career is out of the question living here. Work would have to be ultra-flexible – I can see the only option would be to be self-employed! I would have to think of something and start my own business from home – but don't know where to start!'

'The dressmaking worked well, as I could do it at home and at any time of day'.

5. The Impact of These Financial Changes

Two people did not mention money being a significant stress point and another clearly got some satisfaction from the household's successful budgeting strategy.

'We plan our trips to Inverness around Hospital visits, Respite and other appointments to maximise our savings. If we want anything expensive we save for it. I am proud to say that we have no credit cards or debt apart from the mortgage.'

For the rest of the group financial issues were a constant underlying source of tension and worry – or for some, a significant daily struggle. The main factors were the need for very tight budgeting, doing without things that many

regard as normal parts of life, worries for the future, the attitudes of others and self employment being seen as the only solution to the need for flexibility.

a) Budgeting

'Money and time were prioritised for my son. I would have done anything to help him get well again. The anxiety factor and exhaustion factor are increased because of distance, remoteness and lack of access. Quality of life for the whole family deteriorates due to lack of money and stress and less time for other members and activities and work.'

'The impact of our finances means I have to plan and save for everything, budget and account for the money on a daily , weekly basis.'

'We have had to get used to just managing. We sold an expensive house down south and bought a cheaper one up here so we had some savings to live off, so we get by. We have enough to live on, and I suppose the fact that we have a very restricted lifestyle (well, no lifestyle really) means we do not spend in the same way as others - we rarely go out, don't entertain, do not holiday together etc etc. Life has become very one-dimensional and boring for us both.'

'Making ends meet is a constant struggle; one certainly becomes inventive when food shopping, creating presents for birthdays and Christmas, and eternally grateful for hand-me-downs from friends' children!'

'Days out need to be free – and this child needs lots of activity.'

b) Doing without

This referred to all sorts of things as can be seen from the quotes below – very rarely, or never, going on holiday, rarely buying any new clothes; using second hand shops, depriving children of activities or toys/equipment that would be good for their development, not using care services which were available but for which there was a charge

'My husband, who is self-employed, has been unable to take time off for a holiday for at least five years, as he would lose income. I have fortunately been able to take our children on holiday to stay with a very kind friend for a week each summer.'

'Because of the deterioration in my partner's condition, and my own health, I no longer have the time or energy to do much in the way of routine maintenance around the home, and the house and gardens are becoming very shabby. It would be nice to pay someone to do some of the jobs, but I have to restrict any spend to essential repairs (eg sorting out plumbing problems).'

We have oil fired heating, which was cheap when we moved here but is horrendously expensive now. Central heating oil peaked at ten times its 1998 costs during the summer - rather more than the increase in petrol and diesel

prices. As a result I cannot afford to heat the house throughout the day, and the heating is only on for a couple of hours in the morning and again in the evening. My partner needs warmth as she is immobile, so we use a multi-fuel stove in our sun lounge and basically live in the one room - the rest of the house is stone cold through the day. A bit unpleasant and slightly depressing’.

‘At times I did not have food in my fridge and it was incredible that I could be so in need myself. We are the invisible carers in the economy.

A number of people could see ways of economising or improving their lives, but were unable to put the plan into action for financial reasons.

‘And, obviously, I cannot afford to change our heating to something more efficient. Not that I would know what to go for, but even a more efficient condensing boiler would cost £2-3K to install.’

‘I’m unable to complete our self build house through lack of time and money, and can’t afford a mortgage’

‘Being trapped in unsuitable accommodation, income now so low that a mortgage would not now be possible and with the current difficulty in selling a house, being unable to buy another’

c) Worries for the future

There were different worries for the future as can be seen below.

‘As a carer you cannot afford to save for a rainy day, many mainstay items are considered as a luxury and are outwith budgets stretched by simply trying to get by. Household repairs are a nightmare and need to be balanced against immediate provision of care, you can’t afford to take out loans for fear of not being able to repay them.’

‘I am acutely aware now that if I eat into my dwindling savings it will be much more difficult to replace them. I’m also aware that there will be a life after my partner, since she is unlikely to live for more than another two or three years. This life may be even harder financially as I will lose her benefits, including the Motability vehicle, and my own Carers Allowance. I will be very unlikely to work again, as I will be close to retirement age. For this reason also, I need to protect what I have.’

‘ a main impact is the lack of opportunity to improve earnings and thus enhance future pension payments.’

d) Attitudes of Others

The lack of recognition of caring as an important role in society is keenly felt by several of the group and it affects people in different ways. One father, living with his family in a caravan due to the costs of caring, felt that his children were *‘looked down on by other school kids cos of our housing situation’*

Another carer mentioned the loss of self esteem and control through loss of her own income.

'Now I always have to ask for money from someone else because I don't have any that is my own, now that I have had to give up work.'

'Other people just don't understand our situation - that we could be poor when what they see is my husband with a well paid job and they see me as someone who has chosen not to work because of this, not because I have to be at home for my son.'

e) Self Employment

For those in self employment there were different anxieties:

'I still have to pay full fees to the HSE, the trade organisation and van insurance etc, but may only be able to work part time depending on how things are going at home and according to my wife's health.'

'In the event of a crisis, (as we experienced two years ago due to severe illness, and at times when our son has been in hospital), my husband has had to take time off work – thus there is a loss in earnings, and we end up in a financial situation that we then have to catch up!'

6. Rural Issues

Not surprisingly everyone mentioned that the distances to be travelled by people living in rural areas is greater for almost everything – visits to doctors and other clinical appointments, for everyday tasks like the shopping, getting to school, for visiting friends and for activities, often therapeutic activities like day centres for older people or swimming for disabled children.

a) Transport

The fact that fuel is so much more expensive in rural areas seems doubly unjust in areas where there is no other option for travel. Public transport is either very sparse or non-existent. Or it may be that, as a result of their condition, it is not possible for the cared-for person to use the public transport that does exist.

'As a rural carer everything is expensive, about 20-25% more than Inverness. Fuel is expensive and, if I have to, I only purchase enough locally to get us to Inverness.'

Some people felt that in different circumstances they would have been able to manage without having two cars in the household, but the circumstances of their caring made a second car essential.

'We have lived here for many years because my husband's work is in this locality. Our house is quite remote, very high on an exposed hillside – our nearest neighbour is over a mile away, as is our infrequent bus service,

rubbish collection, and postal delivery. In the winter our farm track is frequently impassable due to packed snow and ice, but we cannot afford a four-wheel drive vehicle. The car I am running at present was bought with a loan from my mother as my car became irreparable – all our mobility allowance is swallowed up by fuel and maintenance costs due to the high mileage we have to cover living rurally.'

b) Other higher costs

It is not only fuel that is more expensive in rural areas.

'Groceries are also more expensive, with fresh fruit and vegetables increasing all the time. I try to purchase my meat from the local butcher and try to buy vegetables only in season and local where possible, this year I started my own growing regime to reduce some of the costs.'

Some people *'rely on online shopping rather than make lengthy and difficult journeys, but will sometimes have to pay an extra delivery charge due to their location.'*

c) Work Opportunities

As we have seen already the distances to centres of population are a major factor in carers' difficulties in finding work that can fit around their caring responsibilities, and thereby limiting their opportunities to earn more of a living.

'Rural carers, however, with the limitations imposed by their lives, suffer the "double whammy" of having to incur the higher expenses, and not having the opportunity of taking action to counter these higher costs through high earning regular jobs.'

'The more rural the carer's situation, the more difficult it becomes. We are only 20 miles from Inverness but there is very little work of any kind out here, let alone work suitable for carers. I don't think many rural employers could realistically offer flexible working hours - most of them are running on the spot to stay in business'.

d) Uptake of Care Services

As well as difficulties with availability of services in rural areas, the distance and cost of the journey to services often influenced decisions about uptake.

'Because there are no suitable care homes near here for my partner's age group we have a long journey to place her in care and bring her home whenever I go away. This can typically be a 60-70 mile round trip, and in addition to the fuel costs, it means I am often unable to do this on the same day that I travel south as it takes too long. This in turn means I have to allow an extra day's respite at each end of my break just to take her to the care home and then pick her up again. Two extra days respite to be paid for and two days off my respite allowance - it all adds up'.

'Attendance at the Autism group means a 70 mile round trip and nearly 6 hrs out of my day, when it has been classed as "respite" for the parents...and no we do not get transportation costs.'

e) Loss of Choice and Opportunity

Other carers spoke about the loss of other types of opportunity and choice in rural areas, referring to the fact that in urban areas people take it for granted that there are choices about the health centre you use, the jobs you apply for, the social clubs you join etc. In rural areas, you are often only able to make these kinds of choices if you have time and money, which many carers do not.

'I would love to attend the study days run about my son's condition and know we would benefit from them, but its not possible to get there.'

'There are also fewer opportunities to share costs with other people if you do decide to travel to another area.'

7. Actions Required from Agencies

As our topic was finance it is to be expected that most people's response to this question was in relation to raising the income available to carers and it elicited some strong feelings. There were several other suggestions covering other aspects of life.

a) Actions required from Central Government

Various mechanisms were suggested for improving carers' incomes, such as improving Carers Allowance to 'a reasonable level, at least equivalent to pension level', paying the minimum wage or the same wage as a support worker, providing the same concessions and bonuses that pensioners get, introducing tax credits for carers.

'The current one size fits all Carers Allowance, at a level below Jobseekers Allowance, is just plain hopeless.'

'Not only should a reasonable wage be paid, but the additional costs of caring should be covered.'

'I think the Carers Allowance needs to be completely overhauled irrespective of whether it is a rural issue or not. £50.55 per week is an insult and sends a clear message to carers that government is happy to take them for granted. CA needs to be restructured so that it acts as some form of income replacement, if not for all carers, then for those who are unable to work because of providing 24x7 care. If government wishes to restrict CA because of employment, then the onus should be on government to prove that there is suitable employment available in the immediate locality, and that enough support is provided to allow the carer to take up employment.'

'Benefits are not increased in line with inflation – nor are our extra costs taken account of'

'Continue to pay Carers Allowance after pension age is reached; we still have the same caring costs.'

Mixed messages were identified in the attitudes of the DPW which it was felt needed to be resolved.

'As a lone parent I found it so hard to cope financially when they put me on job seekers allowance - my youngest was 16. Caring for my son is a life long commitment which has impacted on my life in numerous ways, particularly financially. And when on income support, as Carers allowance is counted as income (at least they recognise it as a job), they take all of it except one small component back again. So, are we working or are we not working?'

There were no negative comments about Disability Living Allowance, although one or two people had difficulty in ensuring it was used in the appropriate way where the cared for person had dementia or learning disabilities, and was not always willing to pay for things that their carers believed they really needed, or would benefit from. These people felt that there should be a better way of them accessing the money in this type of situation.

A couple of people mentioned the amount of money the state would have to spend in order to cover the care of their relative, if the carer were not able to do this.

'in my opinion as a full -time carer to 2.5 people I am actually saving the state a large amount of money per week. They cannot quantify this saving despite my requests and therefore my own estimate is in the region of £1200-1500 per week. Given that my carers allowance payment equates to about 8 pence per hour, you can see the huge disparity in the system. However I would also state that I would not change what I do as they are my family and that's the most important thing to me hence my life choices.'

Another person pointed out that the money she paid for a support worker to take her son out for 5 hours on a Saturday was more than she received for the care of her son for a whole week.

'We need to be getting an amount similar to a care worker, or at the very least the equivalent of the minimum wage'

The carers were not only seeking change in the amount of their income, but their responses also reflect the perceived lack of respect for carers which many expressed, and which has a knock on effect on their self esteem.

'Life is one constant struggle in many ways, sometimes ones self-esteem hits rock bottom, but you have to keep on the "up" as it is the children that are

important. I have often questioned my ability as a carer – usually when exhausted! I feel that over the years of caring for my son I have lost a huge amount of confidence.'

'This needs recognition at central government level. The problems need to be identified, recognised, and addressed by policy specifically targeted at rural carers.'

Other suggestions and comments ranged over other topics:

'Remote rural communities should get fuel subsidy grants for both petrol and oil/coal. Improved infrastructure in road, transport and transport links. Comparable food pricing structure to protect the local business and the consumer'.

Another suggestion to help with the additional costs of fuel was to have free road tax for carers

'Overall there needs to be a culture-change whereby the support for carers (particularly those in remote areas, where health and social services are more expensive to provide) is seen as an investment, rather than a burden.'

'The rules about limits on caring/earning/learning should be altered as they are hindering carers who are trying to improve their prospects for the future.'

'Carers should be able to claim recompense from the estate of the person they have cared for after their death, rather than it being divided equally amongst siblings who have not taken a role in the caring.'

One carer spoke about the anomalies associated with compensation for such situations as accidents at work or injuries at birth. This is a fairly recent, and erratic, phenomenon. Her thought was that all compensation payments should be pooled to be shared by all in equivalent situations.

Another point made was that parents often put 'money by' for the future of their cared-for relative and then find that the relative's benefits are reduced due to these 'savings'. She felt it should be possible to protect this money for the future 'after we are gone'.

'Voluntary groups need to be doing more lobbying for better support for carers'.

'Hospital travel costs should be paid in full'

'There should be a high profile celebrity speaking out for carers, someone who has experience of being a carer'.

'If an alternative therapy is seen to be working, it should be paid for by the NHS in the same way as conventional treatment, along with the transport costs to the treatment centre'.

b) Actions by Local Government and other Local Agencies

The most common comment here was to do with the provision of information. Several of this group of carers' circumstances had improved significantly once they knew about such things as Carers Allowance, refunding of the costs of travel to hospital and carer accommodation, assessment for care. Sometimes these were found out only by chance, rather than being given at least some signposting to sources of help at the time of becoming a carer.

Other suggestions made by individuals, relating more specifically to local agencies were:

'Local government should increase investment in rural transport initiatives which bring major benefits to the disadvantaged in communities, and would be of proportionately higher advantage to carers and those for whom they care'.

'Locally-based respite facilities (be it residential or day care, in a centre or in the home) is a particularly key issue in rural areas'.

'Improve housing to encourage people to move to this area and become support workers, carers and other support areas. '

'Give us the means to help each other. Access to local halls and community spaces, and the means to set up groups relevant to the needs of those in a particular area. It does not have to cost money, as we are a resourceful group of individuals and could tap into a wealth of experience.'

Many of the other suggestions people made were related to the available services and their quality, and these will be recorded elsewhere in the coming months. In general these were pleas for better resources for local authorities to enable them to increase and/or improve local services which support carers, such as more (and free) respite opportunities, filling vacant posts and training for care staff.

8. Charging for Services

Several of the households in the group were being charged for care services. Respite charges had been introduced in the last few years and this was a sore point with some. Where careful budgeting was essential, some people felt it was not the priority and that they could not afford it, or they reduced the amount of respite they took.

'I cancelled 4 weeks of booked respite when charges were introduced because I couldn't see how I would be able to pay.'

'although I myself was previously assessed as requiring 12-18 hrs of care per week with the household chores because of my injury...we cannot afford the £10 + per hour from a budget already taxed to its limit. '

Others felt that respite care should be free as a matter of principle.

'recent changes in charging have a major economic impact, and seem to contradict the concept of investment in support for carers.'

'If we managed to save anything we should be congratulated not penalised.'

One felt particularly strongly about means testing, describing it as *'intrusive and unpleasant'*.

'I often wonder about the fairness of a policy based on age as my partner is so severely handicapped that she is in a much worse state than many people who qualify for free personal care. She is very unlikely to live to see that age, and in the meantime is being discriminated against when it comes to care services. If FPC cannot be provided to all then surely it should be provided based on need, not age.'

9. Closing Remarks

Many thanks are due to the carers who took the time to consider this topic and to put their thoughts into words, either in print or by telephone.

It is anticipated that they will be involved in further discussions before the end of March.