

## **Response to Consultation on Draft Guidance for Respite and Short Breaks**

Carers Scotland is the voice of carers. Carers give so much to society, yet as a consequence of caring, they experience ill health, poverty and discrimination. Carers Scotland is an organisation of carers fighting to end this injustice.

### **Context of Carers Scotland's Response**

Carers Scotland welcomes the opportunity to respond to the Scottish Government's consultation on draft guidance for respite and short breaks. Given Carers Scotland's involvement in contributing to the Guidance through the Respite Task Group, our comments, although following the framework, are largely informed by the analysis of the questionnaire to carers outlined below.

Respite and short breaks have been consistently rated as one of the most important issues for carers and to ensure that their views informed our response, we produced a summary of the consultation document and a questionnaire to enable carers to submit their views. This was disseminated to over 1000 carers and organisations working with carers including carers groups, voluntary and statutory organisations. A further 175 copies were downloaded from our website. Recipients were encouraged to respond through Carers Scotland or directly to the Scottish Government.

In addition, carers and organisation representatives attending our carers' conference "Caring Costs" in December 2007 were provided with information about the consultation including a presentation by Peter Stapleton from the Carers Branch.

### **Response to specific issues raised within the Guidance**

#### **1. Outcomes**

We broadly agree with the outcomes detailed within the Guidance, as did 2 out of 3 carers responding to our questionnaire. However, it may be helpful to highlight the principle of carers as key partners to emphasise the importance of carers being listened to, feeling respected and having their experience and knowledge recognised.

Respondents also highlighted additional outcomes that could be considered for inclusion within the guidance:

- Carers feel supported to work, have a social life and be included in society
- Service users feel supported to have a social life, separate from their parent or carer where preferred and be included in society

## **2. Definition and ways in which respite and short breaks can be delivered**

We agree with the detailed definition of respite and short breaks and, as indicated by one of the 90% of respondents who also agreed with the definition, it would be helpful to change “to provide a break...” to “to provide a high quality break...” In addition, it is important that the correct service is provided, as without this, it is less likely that the purpose can be met.

The issue of a minimum statutory entitlement was highlighted and its inclusion in future respite planning and guidance.

## **3. Value of respite**

The importance of breaks from caring cannot be underestimated and we welcome the clear statement of the value of respite and short breaks. Over 90% of respondents rated breaks to safeguard their own health as one of the most or the most important values. As one carer noted “The value of respite is undeniable. I could do with a few more weeks in the year. My husband is almost immobile, had a hospital bed in my lounge with 2 carers coming in four times a day. I get exhausted.”

Two thirds of respondents agreed that respite had value in all of the stated areas within the Guidance. Critically, the largest proportion – 64% - stated that in order for a break from caring to be effective they must have confidence in the arrangements made to provide this break. This has particular significance for social services in arranging respite provision.

## **4. Planning**

We welcome the clear link between strategic joint planning and the effective delivery of quality respite and short breaks. This is particularly important in meeting the needs of those who receive breaks from caring from both the NHS and social services, 1 in 10 of those who responded.

However, carers did highlight a number of issues of concern. Only 28% were aware of the existence of either a separate respite strategy or one that was part of their local partnership’s community care strategy. The majority of respondents did not have a clear picture of joint working and planning in their area or of whether carers were involved in planning. Of those who did respond, only 8% said that there was good joint working and planning in their area and only a third were aware of the involvement of carers in planning in their area.

- “There is a lack of commitment by the NHS in our area to met the continuing healthcare needs of adults with profound and multiple learning disabilities who also have complex healthcare needs. Currently there is no emergency respite care or outreach for families. Respite care is limited, inflexible and there is no choice of time or length of stay due to lack of funding by the NHS. Families are not getting the number of nights they have been assessed as needing on their Carers Assessment forms. However, the little respite care that has been provided has been of high quality. Health needs to jointly fund and plan with social work, and involved carers and service users in the designing, planning, deliver and monitoring of these services.”

## 5. Types of respite and its relative importance to carers

We welcome the focus on extending choice and flexibility to carers and to those they care for and in the importance of delivering planned, scheduled respite to prevent crises and in planning for emergency respite to respond to crises.

More than half of respondents highlighted the importance of both regular planned breaks from caring and the confidence that emergency respite will be available should an unexpected crisis arise.

We also welcome the factors identified as important by carers in Para 25 of the guidance. Carer respondents reinforced their significance, and stressed the need to have confidence in the quality of care, which was rated as most important.

- “Need good general care by experienced care worker, trust, continuity of drugs, catheter care, etc”
- “Staff would have to be trained, committed, patient, sense of humour, caring... and enough staff to give them the quality of life they have at home.”
- “Short breaks are essential for carers provided that they feel that “those cared for” with dementia will be safe away from home. This is very important to me.”
- “Knowing that my daughter was happy and with someone who is fully trained in caring for her needs would help me greatly. I am not always confident that staff (ever changing) fully know her needs.”
- “More trained staff and better trained staff to support people with Parkinson’s disease. When medication is required it should be administered in line with the care recipient’s own normal daily set time and needed and not the hospital’s or care home’s regime or rules.”

The majority of carers utilised more traditional types of respite and short breaks – breaks in a care home or respite unit, breaks at home and day care services. However respondents were interested in accessing a wider range of breaks, in particular holiday breaks and befriending services, particularly those that helped the person they care for access recreation and leisure whilst the carer had a break.

It was significant that few carers identified direct payments as a means of organising respite and short breaks. This finding mirrors other evidence to suggest that carers are often unaware of direct payments and are provided with little if any information on its available or application. It is suggested that the Guidance include a direction to social care providers to make available appropriate information on self directed care to link to Guidance on Self Directed Care and its user as a means to provide creative respite breaks (see good practice examples on page 4 of this response).

### Observations from carers

- “I have never been offered any respite. I have not had a break for over 4 years”.
- “Breaks where the carer can have the cared for person at home with 24/7 care provided whilst they have a break”
- “Breaks the same as everyone else. Annual holiday in a hotel, short breaks in a B&B etc. I would like to see carers getting a direct payment to pay for the break to enable me to go with my son.”

- “I feel there should be more residential places available for those like my son who are partially self-sufficient but need a bit of help”.
- “Direct payments should be flexible for people with deteriorating conditions e.g. dementia”.
- “Not used – not suitable for people with severe dementia”.
- “Breaks that continue life skills e.g. food preparation, laundry, shopping, and accessing local community. After formal education stops young special needs adults need independent living skills to be constantly repeated.”
- “I recently attended a funeral quite a distance from home. It took a lot of arranging. I had to use friends but if there was some sort of emergency respite it would have taken the stress from me.”
- “I would love to be offered most of the services but even on direct request I am told they are not available.”
- “Holidays where friends can get together with supporting escorts.”
- “Regular overnight care. Maintaining routine and releasing carer for a few days and nights.”
- “I personally feel that my wife is discriminated against for being in a wheelchair. Previous respite hasn’t catered for her needs as were left in a flat with no recreational facilities or choice of things to do. Quite frankly I have refused recent respite for this reason, as it is soul destroying and depressing to be stuck in a flat for a week. Therefore, I have to struggle to save for a holiday that caters for both of us. ”
- “Where a family member could take the user on a holiday as this would be a great way for the user to enjoy a break with someone they know and trust and that the carer can really get peace of mind knowing that it is real respite and not being stuck in a place with people who do not know them.”

The break services that carers were currently unable to access but were interested in receiving or finding out more about included those from the NHS.

Just under 60% of respondents expressed an interest in the role of the NHS in providing respite, for example in day hospitals and in supporting respite by providing services to support the continuing health care needs of the cared-for person, including support to maintain health and cognitive abilities. However, as one carer noted “In my area I am led to understand that a day hospital is not a place to socialise, it’s for people requiring physio. Surely mental stimulation should be considered.”

Only three respondents highlighted good practice examples.

- “Threshold, South Lanarkshire which promotes community integration skills. They now have a system of informing their clients about short breaks for the following year. Very good. They also held a Carers Information Evening at Bells College, Hamilton.”
- “Specifically adapted respite centres for specific illnesses e.g. MS where the nursing care is trained in the conditions and treatment of the illness, therefore ensuring quality of care.”
- “My daughter has been going away to Lourdes once a year for the last 3 years with the Glasgow Pilgrimage. She loves it and looks forward to it. It a great respite for her Dad and I knowing that everything is getting taken care of. Doctors, nurses and volunteer staff are there and we get peace of mind. We get it through direct payments. I just hope it continues as we are both pensioners.”

## 6. Information

We welcome the continued emphasis on the importance of information in enabling carers to access the services they require. Almost half of respondents found information about respite easy to find and over a third had received a range of information, which had been helpful or partly helpful. However, the responses do show a varying picture with around 20% of carers not receiving any information about respite and short breaks.

- “Information/advice from the outset is missing – it is very important to ensure there is a system that kicks in with the caring role to give this information. I soldiered on for 4 years before being told very off-handedly “oh you’re entitled to 56 days respite care a year”. Yet the same social worker, community nurse and doctor were involved from Day 1.”

## 7. Eligibility criteria

We acknowledge that at times when resources are limited, eligibility criteria are a necessary requirement and believe that the carers identified as “most at risk” are broadly correct as do almost 80% of respondents.

However, the following additional criteria of carers who are most at risk have been suggested:

- “include carers of people with language and communication difficulties.”
- “carers of young people/people with complex health needs – the level of personal and nursing care over a 24 hour period can be quite intensive in these situations.”
- “priority for single parents and widows/widowers. I am a widow and care for my daughter on my own 24/7.”

However, eligibility criteria may exclude carers who are in great need. As with all Guidance it is important that “gatekeepers of services” apply the criteria flexibly, taking account of individual circumstances and promoting a preventative approach. As one carer noted “all carers should be treated equally. I have a child with a learning disability and am married. At my previous local authority only single parents were offered support.”

We welcome the inclusion of the importance of services, including breaks from caring, to enable a carer to remain in or re-enter employment. We know that the absence of this support can have significant negative impact on carers’ circumstances, for example, finances, pensions, health and involvement in the wider community.

We hope that partnerships will fully involve carers in the development of eligibility criteria as part of their wider planning responsibilities. It is important that carers are actively involved in all aspects of service design, delivery and review. We would therefore welcome a strengthening of this sentence to further encourage partnerships to take this forward.

## 8. Monitoring, Quality Assurance and Review

Monitoring, quality assurance and review remain critical to ensuring the success of this guidance within individual partnerships.

Without robust, transparent and measurable criteria to evaluate the implementation of this Guidance and its effectiveness, the impact will be dissipated causing immense frustration and little change to the quality of carers' lives.

In the light of the above and the new Concordat between the Scottish Government and local authorities, we are concerned that local improvement targets and national outcome measures will be lost with no alternative measures in place.

Although the Concordat will involve reporting on progress of the delivery of 10,000 extra weeks of respite, it would be helpful to make explicit the ways in which existing service levels and the development of more flexible, varied and personalised respite and short break services will be monitored and evaluated.

## 9. Charging

Carers Scotland's position remains that carers should not be charged for services that support their caring role. We welcome Para 44 which notes the principle of working with carers as key partners of care and the possibility that charging systems can result in poor uptake of respite services.

Respondents support this position, with a third reporting that service charges are too expensive and that this has discouraged them from using respite services. One in five have turned down a respite or short break service because they are unable to afford the charges levied. The implications of this are extremely concerning not only for carers but for those they care for.

Notwithstanding the above, we do welcome the statement that charges for adult services should not extend to families or carers. However, CoSLA guidance on charging for home care services contradicts this and Carers Scotland and the Coalition of Carers in Scotland have met with CoSLA in attempt to highlight this anomaly in their guidance to local authorities. It is essential that Guidance is consistent.

- "£600 per week for respite care – I am over 60 years old. I do it for no cost or free!"
- "Assessment should be on all income and expenditure... this is not done and we have found that they say we can afford to pay when in actual fact we cannot due to extra costs not being taken into account."
- "My son lives on state benefits. I get £48.65 Carers Allowance, which will be taken away next year when I turn 60, although I will still be caring. To charge is a national disgrace..."
- "Respite should be free."
- "instead of leaving my life in respite to take a holiday with my teenage daughter (because of cost) I had to take her with me, which kind of defeated the object."
- "Befriending service too expensive - £10.50 per hour."
- "I live in a different area local authority from my mother. In her area she pays a minimal amount to a local authority care home for occasional respite. In my area it is all private and would cost £600 a week – totally out of the question."
- Full funding should be made for respite breaks and carers should not have to pay. The amount of money that carers receive to care 24/7 is not enough to make ends meet. If you have a mortgage, utility bills, etc. having to find extra money to pay for respite is a struggle."

A significant issue for carers, particularly those in rural areas, is the issue of transport. Currently, the cost of transport to and from respite is not always met by local authorities, sometimes making it impossible for carers to make use of the services available. It is essential that the costs of transport to and from respite be included as part of the respite package.

In addition to the above, it is important to recognise the provision of appropriate transport lessens the expectations placed on carers and allows them to receive the full benefit of a break.

- “Transport costs should be included in assessed need to get the person to and from respite. At the moment, local authorities do not provide this. I had to provide transport to Aviemore for my daughter from Motherwell. Local authority paid the respite costs but not the £180 transport costs. Was told I could take two days off my work to get her there and back.”

#### **10. Indicators of good respite care**

We welcome and agree with the indicators of good respite care, as did 96% of respondents. However, the indicators should highlight that when planning respite it should also be considered whether it is appropriate to the age and culture of the carer.

Reliability was also noted as an important indicator, including providing alternatives when services such as day care are closed on public holidays.

- “What is the definition of “affordable”? What may seem to be affordable by the local authority may not be seen as such by the carer...”
- “Free respite would definitely mean a wider uptake but I fully accept all resourced have to be costed in a balanced way with priorities made.
- “Continuity in respite as in personal care is the name of the game.”

**The following additional issues were highlighted by carers.**

#### **Equity of Service**

- “Services vary from area to area. For example, in Glasgow we cannot have befrienders but in surrounding areas, these are readily available. I would love my daughter to have social activities which did not involve me transporting her. She needs a break from me and me from her.”

This comment reflects the experience of Carers Scotland that the level and quality of service provision is very varied across Scotland. It is essential that access to services is not geographically determined or dependent on the vagaries of differing local authority policies.

#### **Accountability and Quality of Service**

- “You should be able to get better recourse from your social worker... many times they withhold information because they know they do not have the budget...”

- “I stopped respite breaks because the care home staff were not capable of looking after my Mum. When this went wrong they never made any attempt to listen to me and put things right. I was labelled as a nuisance and troublemaker by the home and social services. Mum is at home all the time now and I have one day off a week paid for by direct payments. I am not young myself but with the help of my husband we just about cope. If carers were listened to and consulted more life would be a lot easier for many of us. We are treated as worthless.”
- “I have nothing but gratitude and admiration for the team who helped me with respite for my husband but there can be personality clashes and I would like to think that, had that been the case, it would have been possible to ask for a change of social worker or individual care worker, without offence being taken.”

These comments strengthen the need for the Guidance at Section 8 to be effective in securing significant change.

### The Guidance

- “On paper it (guidance) looks very good. Getting reliable respite for my mother is impossible, so we now don’t have a break. If it’s out there we haven’t found it yet. We’ve cancelled holidays after leaving my mother in care for two days. We have had catheter disasters, filthy rooms, staff from the streets without any training, given other patient’s drugs and none of her own, infections – shall I go on?”
- “The criteria for good practice set out in the guidance should be a **requirement**. Respite provision should be monitored regularly. Service user feedback should be a key feature of monitoring and review. Funding **must** be forthcoming to make all this possible.”
- “It would be wonderful if these guidelines were actually embraced and effective. Over the years I have lost count of the number of times I have been asked what I think good respite would be. Nothing seems to change except another committee and another questionnaire not only by yourselves but also by other agencies. Hopefully some pressure will be put on local authorities to at least include carers when planning services not just volunteers who have time to attend meetings which many full time carers do not.”

Carers Scotland supports the above views. It is essential that the Guidance is not seen simply as an exhortation to good practice but rather an exposition of the key requirements of an accessible, personalised and effective range of resources to support carers as key partners in the delivery of social care in Scotland.

Carers Scotland  
15 January 2008

## Appendix 1

### Profile of respondents

#### Local Authority area:

- Aberdeen City 2%
- Aberdeenshire 11%
- Angus 4%
- Argyll 2%
- Edinburgh City 9%
- Clackmannanshire 2%
- Dumfries & Galloway 5%
- Dundee City 5%
- East Ayrshire 2%
- East Dunbartonshire 2%
- Fife 5%
- Glasgow 4%
- Highland 2%
- Inverclyde 4%
- Moray 2%
- North Lanarkshire 4%
- Orkney 2%
- Perth & Kinross 4%
- Renfrewshire 14%
- Scottish Borders 2%
- Not given 18%

#### Caring for:

- Spouse/Partner 39%
- Son or Daughter 37%
- Parent 7%
- Not given 18%

#### Cared for person affected by:

- Alzheimer's/Dementia 9%
- Learning Disabilities 23%  
(including autism, profound and multiple disabilities and brain injury)
- Physical Disabilities 23%
- Parkinson's 4%
- MS 4%
- Mental Health 9%
- Stroke 12%
- Not given 18%

