

# **CARERS** look after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid.

## **POLICY BRIEFING**

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### Rural Carers

Date July 2003

Relevant to: UK

#### **1. Background**

A rural area is usually defined as a community of 10,000 people or less. There are no exact figures for numbers of rural carers, however:-

In England the National Strategy for Carers<sup>1</sup> states that roughly 1 in 5 people live in rural areas. Given that there are 5 million carers<sup>2</sup>, this means that nearly 1 million carers live in rural areas.

In Northern Ireland just under 700,000 people live in rural areas.<sup>3</sup> 2001 Census figures show that 11% of the population are carers, which means there are approximately 75,000 rural carers in Northern Ireland.

In Scotland 1.5 million people live in rural areas.<sup>4</sup> 2001 Census figures show that 10% of the population are carers, which means there are approximately 150,000 rural carers in Scotland.

In Wales there are no figures for the rural population in Wales, but large parts of Wales are rural and it is likely that a large proportion of Wales' 340,745 carers live in rural areas.

#### **2. The Current Situation - Problems**

Carers in rural areas have the same needs as carers living elsewhere. However, the rural setting in which they live means they face extra barriers of physical and social isolation and lack of services. Additional problems include:-

- Lack of services available
- Lack of specialist services
- Lack of respite
- Difficulty in accessing medical support
- Isolation and Companionship
- Lack of Privacy
- Information
- Lack of alternatives to family care
- Poverty and additional cost of living in a rural area
- Transport
- Employment

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**CARERS** UK

### **Lack of services, lack of choice, lack of specialist services**

Services tend to cost more due to distance needed to travel to and within rural areas. This often means that rural carers are on the bottom of the list for certain services, leading to a lack of choice, flexibility and support. Due to the low numbers involved, there are often shortages of specialist housing, residential and day care. Carers who need specialist services, such as ethnic minority carers or those supporting people with rare conditions and those caring for people with 'stigmatised' illnesses such as mental health or AIDS will have additional problems getting the services they need.

### **Access to respite and medical services**

Research shows that 52%<sup>5</sup> of full-time carers are never able to take even a week's break from their caring responsibilities. Rural carers also need long sitting services compared to urban carers, because it takes longer to get anywhere.

Research<sup>6</sup> indicates that older people living in rural areas visited hospitals less frequently, and usually when their illness was more advanced. Only 25% of those living in rural areas live within 5 miles of out-patient appointments, compared with 70% of carers in cities.<sup>7</sup> Rural carers stress the importance placed on GPs making home visits and highlighted the difficulties faced with the closure of community hospitals.<sup>8</sup>

### **Isolation, companionship and privacy**

Carers UK's recent survey of its members found that 57% of respondents living in 'remote rural areas' suffered from some form of social exclusion. Or, to use carer's own words "I'm 13 miles from the nearest town and can't afford transport or phone. I'm miserable as Hell."<sup>9</sup> It is very hard to establish mutual carers' support in remote areas, due to the distance between carers, lack of transport and privacy issues.

Providing services through local means can compromise carers' privacy. Carers may fear being stigmatised by the local community, particularly if caring for a person with mental health, or drug/alcohol problems. In Suffolk, for example, some carers prefer to visit carers' support groups in a neighbouring village or town rather than services in their own community.

### **Alternatives to family care**

Four out of five rural carers considered that they had no 'real choice' about whether to take on their caring roles<sup>10</sup>. There are few alternatives to carers in rural area and carers tend to be reluctant to look for them due to pressures of portraying images of coping and caring.

### **Information**

There are very few contact points for information meaning that provision of information can be more difficult.

### **Social Exclusion: poverty, employment and transport**

The combination of low pay<sup>11</sup>, high transport costs and the high cost of goods and services in rural areas means that many rural carers face the additional problem of living in poverty. Caring on the Breadline<sup>12</sup>, Carers UK's research into the financial situation of carers, identified the difficulties carers face living in rural areas due to the cost of public and private transport. Yet many carers also lack the resources to run a car. "As I live in a rural area, a car is a necessity to get my husband out of the isolation that disability can create, but the cost of running the car and repairing it is a drain on resources and a constant worry."<sup>13</sup>

Employment is often seen as one route out of social exclusion. Carers in rural areas, however can find it more difficult to combine paid work, or training and care, due to the lack of transport and difficulties in obtaining support services.

### **3. Problems facing agencies serving rural carers**

- High unit cost of providing services
- Difficulties in consulting rural people
- Rural users and carers may be reluctant to ask for help
- Lack of reliable data about needs of people who live in rural areas
- Staff recruitment/retention problems – "It is still the rural problem. Not being able to recruit staff as helpers for carers in rural villages."<sup>14</sup>
- Problems disseminating information
- Privacy issues when using shared buildings - ensuring that client records are stored securely
- Poor take-up of services, due to the transport, privacy and other reasons mentioned above.

### **4. Legislation and Guidance**

There is no separate legislation for carers in rural areas, though the following have relevance:-

**Carers and Disabled Children's Act 2000**<sup>15</sup> (England and Wales)- Under the Act services can be provided directly to carers, including help with shopping and paying for carers to have driving lessons. The Act also enables carers to receive direct payments, which could be used by the carer to buy in support locally.

**Rural White Paper: Our countryside the future**<sup>16</sup> (England) - Includes a commitment to innovative ways of delivering services to those in rural areas; using new technology, sharing buildings, using mobile units and offering appointment bookings that take account of distance people need to travel.

**National Strategy for Carers**<sup>17</sup> (England)- recognises that carers in rural areas find it more difficult to access advice and assistance and promises that all carers should have access to a local carer support service. It also recognises the need for improved rural transport and requires those planning local rural regeneration

projects to involve carers in developing proposals.

**Scotland Strategy for Carers**<sup>18</sup> – States that local authorities should consult local carers on providing flexible quality services.<sup>19</sup> There is also a commitment to provision of information via leaflets, local radio, NHS helpline and website, “which are of particular benefit to carers in remote rural areas”.

**Valuing Carers – A Strategy for Carers in Northern Ireland** – No specific reference to rural carers, but the Strategy recognises the need for a “range of flexible, practical support” “tailored to fit the needs of users and carers.”

**Wales Strategy for Carers** – recognises that carers in “rural and remote” communities face “added difficulties” and is committed to create opportunities for carers to use their breaks, including support from the Welsh Rural Transport Grant Scheme and the Community Transport Association.

**Fair Access to Care Services**<sup>20</sup> (England)– Assessments will take account of the impact on people’s living arrangements, including their independence and type of help they need. Assessments should include an “evaluation of risk”. Under paragraph 40 of the Guidance, risk includes all areas of ability to function in the community, including hobbies and work.

## 5. Good Practice and Solutions

### Increasing take-up of benefits

- For Carers Rights Day 2002 the Carers Forum for Learning Disability in Warwickshire ran buses for carers in rural areas to take them to benefits advice sessions around the county.

### Improving access to information

- Carers Online is a website run by Carers UK, which combines national information with links to local information provided by authorities signed up to the project. Carers can also access Care Radio, a radio service for carers.
- In Derbyshire an information kiosk was set up at a local cattle market<sup>21</sup>.
- The Rural Minds Project<sup>22</sup>, ran by MIND, links local projects and carers through a journal, conferences and online discussion groups. The Connecting Minds Project uses teleconferencing to link services users and a trained facilitator to enable carers to communicate with people in a similar situation without any of the difficulties associated with organising carers’ groups.

### Tailored services

- In Suffolk, flexible use of the Carers Grant has ensured that rural carers get the respite services they need; including home tutoring on computers, home sitting services, carers courses provided locally.
- In Lancashire, a local taxi firm ran by Asian people was used to take Asian people to day centres<sup>23</sup>.

### Transport

- Babergh District Council have set up a Buzz Around service, to pick carers and services users to doctors appointments, shopping, etc. and has also been used to take carers to consultation meetings.

### **Improving service levels**

- Bedfordshire Social Services buy in day care from neighbouring Social Services Departments where this is nearer to need.<sup>24</sup>
- In Tyrone and Fermanagh Age Concern's Rural Action on Dementia Project provided day-care in 4 rural centres tailored to local need, as an effective means of providing respite for carers.<sup>25</sup>

### **Flexible provision of specialist medical care**

- In Lancashire, day care facilities are used to provide additional services such as visits by GP and district nurse, and in East Sussex day care facilities have been used for providing specialist services such as eye testing and chiropody.<sup>26</sup>

### **Joint Working**

- In Wiltshire, 70% of GPs services have a linked worker from Social Services.<sup>27</sup>

### **Consultation**

- In Wiltshire, consultation takes place with 19 community areas, with staff appointed with responsibility for facilitating rural carers' and users' access to consultation and planning meetings.

### **Reaching 'hidden' carers**

- The Northern Fells Rural Project in Cumbria reached isolated carers in seven target areas through articles in a parish magazine and local GPs surgeries.<sup>28</sup> Carers were helped to claim benefits and services, there were local lunch clubs and practical help via a handyman and domestic support scheme.

### **Innovative local carers' groups**

- The PRTC Highland Carers Project supports carers groups across the Scottish Highlands by providing training for volunteers and a free helpline for carers.
- Suffolk Carers Centre use volunteers to take carers to local carers centres, and staff are based in rural locations, e.g. local hospitals or working from home, to minimise the time spend travelling

### **Helping carers back into employment**

- The ACE National project includes pilot sites in Anglesey and Carmarthen, looking at ways of supporting carers in these rural areas wishing to continue in, or return to, work.

## **6. Carers UK's Recommendations**

Local authorities, NHS Trusts and PCTs should:-

- Develop strategies to identify and address rural carer issues
- Audit the impact of services currently provided and involve carers in the development of new services
- Budget for the 'rural premium' – i.e. accept that it will cost more to provide equality of service for those in rural areas
- Planning – build in the needs of rural carers to all service planning
- Training – ensure that staff understand the impact of rurality
- Provide information online, sign up to the CarersOnline project

- Share good practice via the CarersOnline bulletin board
- Joint working – can bring services closer to users and carers by utilising the nearest available buildings
- Take part in Carers Rights Day, Carers UK’s benefits and rights awareness day. Carers Rights Day 2003 takes place on 5 December.

## **7. What Carers UK are doing**

- Raising awareness of the issues facing rural carers
- CarersOnline website provides high quality national and local information and enables sharing good practice via the bulletin board
- CarersLine – provides a free advice and information to callers throughout the UK (0808 808 7777, Mon-Fri 10.00 – 12.00 and 2.00 – 4.00)
- Campaigns, including Carers Rights Day, which raises awareness of carers’ rights and promotes take-up of benefits and services
- Research – identifying statistics on rural carers in all pieces of research
- Action for Carers and Employment (ACE National) – Carers UK are co-ordinating a national project investigating way of supporting carers in employment, includes pilot sites in rural areas.

## **8. Recommended Reading**

**A Country Mile: The Distance Between Rural Carers and Services**, West of Scotland Carers’ Forum

**Care in the Country** – Inspection of Community Care in Rural Communities, Social Services Inspectorate, Department of Health, 1999.

**How do Communities Care?** - PRTC Highland Carers Project, 1998

**Supporting Rural Voluntary Action: A ten point plan** – NCVO, 2002

**Public Service Delivery and the Voluntary Sector: The Rural Analysis**, NCVO 2002

**The Way Ahead for Rural Services: a guide to good practice in locating rural services**, Department for Environment, Food and Rural Affairs, 2002

**Caring for Rural Carers Survey Report**, NFWI, 1993

**Service Provision for People with Dementia and their Carers in Remote and Rural Areas of Scotland**, Dementia Services Development Centre, 2003

## Useful websites:-

Carers Online - [www.carersonline.org.uk](http://www.carersonline.org.uk)

Suffolk Carers - [www.suffolk-carers.co.uk](http://www.suffolk-carers.co.uk)

PRTC Highland Carers Project - [www.hccf.org.uk/projects/PRT](http://www.hccf.org.uk/projects/PRT)

West of Scotland Carers' Forum – [www.wscf.info/rural.htm](http://www.wscf.info/rural.htm)

## 9. References

- <sup>1</sup> National Carers Strategy, Department of Health, 1999
- <sup>2</sup> Office of National Statistics, 2001 Census
- <sup>3</sup> Shaping our Future – Regional Development Strategy for Northern Ireland 2025, Chapter 8
- <sup>4</sup> General Register Office for Scotland, Population and Population Density, 1998
- <sup>5</sup> Caring for Rural Carers Survey Report, London, NFWI, 1993.
- <sup>6</sup> Bentham & Hayes at the University of East Anglia
- <sup>7</sup> Ignored and Invisible, Carers UK, 1998 p.38
- <sup>8</sup> *ibid*, p.43
- <sup>9</sup> Carers UK Membership Survey 2002 (unpublished)
- <sup>10</sup> Caring for Rural Carers Survey Report, London, NFWI, 1993.
- <sup>11</sup> Redressing the Balance, Carers UK, 2002, p.6
- <sup>12</sup> Caring on the Breadline: The financial implications of caring, Carers UK, 2000
- <sup>13</sup> *Ibid*, p.16.
- <sup>14</sup> Carers UK Membership Survey 2002 (unpublished)
- <sup>15</sup> The Carers and Disabled Children Act 2000 policy and practice guidance and the practitioner's guide to assessments can be obtained from [www.carers.gov.uk/zone9.htm](http://www.carers.gov.uk/zone9.htm).
- <sup>16</sup> Rural White Paper, Our Countryside the Future, Department of Environment, Food and Rural Affairs, 2000
- <sup>17</sup> National Carers' Strategy, Department of Health, 1999
- <sup>18</sup> Scotland National Strategy for Carers, Scottish Executive, 1999
- <sup>19</sup> *Ibid*, p. 5
- <sup>20</sup> Fair Access to Care: Guidance on Eligibility Criteria for Adult Social Care can be found at: [www.doh.gov.uk/scg/facs](http://www.doh.gov.uk/scg/facs) or ordered from Department of Health Publications
- <sup>21</sup> Care in the Country:- Inspection of Community Care in Rural Communities, Social Services Inspectorate, Department of Health, 1999
- <sup>22</sup> Rural Minds Digest, Issue 50, December 2002
- <sup>23</sup> Care in the Country: Inspection of Community Care in Rural Communities, Social Services Inspectorate, Department of Health, 1999
- <sup>24</sup> *ibid*
- <sup>25</sup> Joseph Rowntree Foundation, Social Care Research Findings 72, August 1995.
- <sup>26</sup> *ibid*
- <sup>27</sup> *ibid*
- <sup>28</sup> Community Care, 'Further Afield', 9 May 2002.

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