

Tackle carer poverty by:

- Helping *younger carers* aged between 18 and 25 by raising the level of the income support personal allowance to that of young people who are disabled or lone parents;
- Helping *parent carers* by including disabled children as a key group in the goal of eradicating child poverty;
- Helping *older carers* by improving disability benefits, and introducing a 'health and wealth' check, including entitlement to potential benefits and services for carers and disabled people over pension age;
- Helping *working-age carers* with their future pensions, and meeting the costs of substitute care whilst the carer is at work through direct payments made to the disabled person to buy in the extra support required;
- Tackling the tensions in the overlap between the carer's invalid care allowance and the disabled person's severe disability premium;
- Helping carers to save, improving the Child Trust Fund/Savings Gateway.

Tackle service exclusion by:

- A more uniform service from each social services department, including a revised funding formula and a Human Rights Act perspective in the planning and provision of services for carers;
- Introduce holistic carer assessments to identify those most at risk of social exclusion, better welfare rights advice and support to stay in or get work. More uniform, and quicker, carer assessments;
- A more proactive approach by primary care groups and hospital trusts to identify and support carers, including training and carer awareness;
- Offering 'out of hours' support services to working carers;
- Providing extra information and technology for carers.

Tackle employment exclusion by:

- Encouraging flexible employment practice by employers and support services;
- Appointing specialist Personal Advisers for carers in Jobcentre Plus, filling the 'carer gap' in the New Deals;
- Extending the employment tax credit to carers, to help carers stay in work for longer and combine work and caring, and help carers over age 50 and former carers who might otherwise have difficulty returning to work.

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- 4 see note 1
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- 9 S Becker, 'Carers and Indicators of Vulnerability to Social Exclusion', *Benefits* 28, April/May 2000
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- 11 see note 1, and G Parker and D Lawton, *Different Types of Care Different Types of Carer: evidence from the General Household Survey*, SPRU/The Stationery Office, 1994
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- 16 R Chamba et al, *On the Edge: minority ethnic families caring for a severely disabled child*, Joseph Rowntree Foundation/The Policy Press, 1999
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- 20 see note 7

Paying the Price:  
carers, poverty and  
social exclusion

By Marilyn Howard.  
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# Paying the price

carers,  
poverty  
and  
social  
exclusion

An estimated 15 per cent of adults over the age of 16 provide unpaid care to an elderly, ill or disabled person who cannot manage without assistance.

This report, commissioned by Carers UK and published by CPAG, highlights aspects of poverty and social exclusion that affect carers. Drawing on research and statistics, it explores issues affecting carers across the lifecycle – from caring at a young age to older carers over pension age – and the transitions into and out of caring, making recommendations for change.



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## Carers and transitions

In Britain, an estimated 5.7 million people are carers:<sup>1</sup>

- ◆ 58 per cent provide care to someone in another household;
- ◆ 8 per cent look after more than one person;
- ◆ 22 per cent are over pension age;<sup>2</sup>
- ◆ One in four have been providing care for ten years or more.<sup>3</sup>

Around 1.7 million people provide ‘substantial’ care, ie, for more than 20 hours a week.<sup>4</sup> By the age of 75, almost two-thirds of women and half of men can expect to provide one or more spells of at least 20 hours of care per week.

As well as long-term caring, about 40 per cent of carers start or end a period of caring each year, and the turnover is higher where people provide care to someone in another household.<sup>5</sup> In any one year about 300,000 adults in the UK become carers.

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## Carers and poverty

Carers often live on low incomes – they may have given up work or are over pension age and living on a fixed income. In 1997, about half of carers providing more than 35 hours of care a week were living on £50 a week or less before benefits.<sup>6</sup>

Carers may also bear some of the costs incurred by the disabled person; two-thirds of carers surveyed by Carers UK attributed their financial difficulties to the additional costs of disability;<sup>7</sup>

*‘My husband is now incontinent. My electric and water and gas bills have increased, ie lights are on all night, extra washing (clothes), extra baths.’*

The Carers UK survey, *Caring on the Breadline*,<sup>8</sup> found that:

- ◆ one in five carers were cutting back on food;
- ◆ almost one in three had trouble paying household bills and had experienced debt;
- ◆ nearly four out of five found the level of charges for services caused financial difficulties;
- ◆ more than two in three carers worried most, or all, of the time about their finances;
- ◆ two in three carers believed that this worry affected their health.

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## Carers and social exclusion

Some carers can be particularly vulnerable to social exclusion, such as:

- ◆ carers living on benefit for long periods;
- ◆ those caring full time or living in the same household as the disabled person;
- ◆ those in poor health;
- ◆ those who have not had a break;
- ◆ carers from minority ethnic groups.<sup>9</sup>

### Carers can be excluded from social activities

Over three-quarters of carers told Carers UK they gave up holidays, leisure pursuits, or family celebrations because of their caring responsibilities:<sup>10</sup>

*‘I cannot afford to travel to family celebrations and buy presents to mark such occasions; worse still, I cannot afford to travel to family funerals or to make commemorative donations or to buy flowers!’*

### Carers can be excluded from services

Official surveys have shown that:

- ◆ almost half of carers providing more than 20 hours a week assistance had had no break since starting caring;
- ◆ 75 per cent of co-resident carers were looking after someone who did not receive any regular visits from health or welfare professionals;
- ◆ people being cared for by relatives were less likely to receive services.<sup>11</sup>

Without help from statutory services, carers may have to pay for services or equipment themselves or go without:

*‘I even have to buy incontinence sheets – £8 per week – as the NHS will not provide them.’*

### Carers can be excluded from paid work

Almost six out of ten carers surveyed by Carers UK had given up work to care, and four in five carers believed they were worse off financially since becoming a carer:<sup>12</sup>

*‘I now only get a quarter of what I used to earn but still have to pay bills at the same rate.’*

There are many carers and caring relationships, which are not all one-way, as the disabled person’s contribution to caring can often be neglected.

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## Young and younger carers

As many as 50,000 children and young people under age 18 could be providing care to another family member – often a parent. A study of carers aged between 16 and 25 found that half were living in lone-parent families, most families were out of work and living on benefit.<sup>13</sup>

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## Parent carers

Fourteen per cent of carers are looking after a disabled child or young adult, and may spend many years caring. Almost 500,000 children and young people in the UK have a disability or long-term illness.<sup>14</sup>

National surveys of parents caring for disabled children found that:

- ◆ parents were less likely to work because of their caring responsibilities;
- ◆ nine out of ten lone parents and over a third of couples had no income other than benefits;
- ◆ many incurred additional costs, such as for laundry bedding and heating;
- ◆ one third of parents said their disabled children had needs they could not meet, such as for clothing, bedding and food.<sup>15</sup>
- ◆ ethnic minority families caring for a severely disabled child had even lower incomes, higher costs and greater levels of unmet need.<sup>16</sup>

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## Working-age carers

The ‘peak age’ for caring is 45-64, accounting for nearly half of carers.

Many carers are without work:

- ◆ Over one in five of couples without work cared for someone other than their own children because of illness or disability (often their partner), compared with only 10 per cent of couples with ‘moderate’ incomes.<sup>17</sup>

- ◆ During the 1990s, the proportion of non-working couples caring for a disabled child almost quadrupled, and those caring for a disabled adult doubled.<sup>18</sup>

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## Older carers

One in four carers (about one million) are over the age of 65, and around 500,000 of these are looking after someone aged 75 or more, often a spouse.<sup>19</sup> Older carers were more likely to be paying for alternative care out of their savings, and more likely than younger carers to attribute their worsening finances to paying charges for community care services.<sup>20</sup>

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## Main recommendations

Policies and resources could be targeted at people providing substantial amounts of care, and for long periods, who are more at risk of poverty and social exclusion, as well as supporting people during transitions into and out of caring.

### Support for carers providing substantial care

- Improved financial help, such as a higher rate and a long-term rate of invalid care allowance, and lump-sum payments to carers on income support for two years.
- The costs associated with caring, many of which are disability-related, could be reduced through improved council tax discounts and transport concessions for carers.
- Health and social care agencies could be more proactive in identifying carers, anticipating when unpaid care is likely to be needed (such as following a hospital stay) to offer timely support to carers.

### Support during transitions

- Policies to help with the transition *into* caring include better signposting by agencies, a more holistic carer assessments by social services, and an emphasis on job retention.
- Help with the transition *out of* caring could involve benefit ‘run-ons’, continuing support services for ex-carers, including a ‘gateway’ for former carers claiming jobseeker’s allowance, and more pension credits for time spent caring.