

## **Health Inequalities - Access to Services**

### **Carers Scotland**

There are 660,000 carers in Scotland. 115,000 of these carers care for at least 50 hours a week. Carers face multiple challenges to their health and wellbeing simply because they are caring. These are exacerbated by poverty (including fuel poverty), loss of employment and lack of services to support them in their caring role.

Carers are a third more likely to be in poor health than non-carers<sup>1</sup>. In some areas, for example, Glasgow City this increases to becoming twice as likely to be in poor health. 18% of those undertaking more than 20 hours of unpaid care a week reported that they are in poor health.<sup>2</sup>

The incidence of caring is greater for those living in deprived areas. The largest proportion of households with a carer (28%) are in the 20% most deprived data zones<sup>3</sup>. The proportion of households with a carer decreases steadily as deprivation decreases, so that households in the least deprived 20% of data zones are those with the lowest prevalence carers in Scotland (13%).

Caring also has significant impacts on finances and employment. Our latest research<sup>4</sup> found that vast numbers of carers are accumulating unmanageable debt as they struggle to cope with loss of income, savings and benefits alongside rising everyday food, fuel and care related bills.

For example, 47% of carers are in debt as a result of caring and almost half are cutting back on essentials like food and heating; 59% are in fuel poverty. 60% of carers said that they are neglecting their diet, a third because of time and a quarter because they cannot afford a balanced diet.

170,112 people in Scotland had given up work to care at some point. Half of working-age carers live in a household with no-one in paid work.

Research has consistently evidenced that caring can have a negative impact on health and wellbeing. In a survey of carers in 2013<sup>5</sup>, 83% said that caring had a negative effect on their physical health and 65% that it had a negative impact on their mental health. A quarter had suffered an injury.

Carers are affected in a range of ways including anxiety and stress (91%), depression (53%), injury such as back pain (36%), high blood pressure (22%) and the deterioration of an existing condition (26%).<sup>6</sup>

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<sup>1</sup> Census 2001

<sup>2</sup> Caring in Scotland: Analysis of Existing Data Sources on Unpaid Carers in Scotland, Scottish Government 2010

<sup>3</sup> Scottish Index of Multiple Deprivation

<sup>4</sup> Caring and Family Finances, Carers Scotland/Carers UK, 2014

<sup>5</sup> State of Caring, Carers Scotland/Carers UK, 2013

<sup>6</sup> In Sickness and in Health, Carers Week Consortium, 2012

Carers often experience barriers to accessing the healthcare they need. This includes primary care, acute care including in the planning of scheduled operations and in follow up support, for example, physiotherapy.

*"I had to postpone a hysterectomy by five months because the person I was caring for needed treatment for cancer"*

*"I have put off going to see the doctor as I am worried that I will need an operation. How will I cope then?"*

Finding time to attend regular medical appointments when you are caring for someone can be difficult. Added to this nearly half of people caring juggle this care with full or part time work. Two out of five carers report that they have put off medical treatment<sup>7</sup>. For half of these this made their problem worse or extended the time for which they were affected by this problem. For 1 in 5 it caused an additional illness and a quarter that it stopped or made their caring harder.

Carers reported: delayed diagnosis of cervical cancer; an untreated cough became acute bronchitis which affected lung function for 8 months; delaying operations including one carer who put off an operation on their bowel which resulted in the need to remove part of their bowel. Missing or delaying medical appointments included delaying dental treatment necessitating tooth loss and decay which may not have developed if carers had sought treatment sooner.

*"I should have an operation but it is so hard to bring everything together, when I finally managed it my blood pressure was too high to go ahead."*

Carers are aware that they needed to look after themselves but often find it difficult to do so. For a number of carers just finding the time to make an appointment or finding someone to look after the person they care for in order to attend the appointment proved impossible.

*"I suffer from osteoporosis, scleroderma and Raynaud's disease. To treat the scleroderma I have to have special treatment every so often or I'll die basically. Once I put it off and contracted gangrene in my finger. To receive the treatment I have to go to hospital for five days at a time and so try to arrange the treatments for during school holidays so my son, who is a teacher, can take care of his Dad."*<sup>8</sup>

*"I need an ankle replacement but surgery is impossible as I would be in plaster for 12 weeks and I am the sole carer."*

It is clear that carers do not feel that appropriate social care support and services are available to enable them to attend routine primary care

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<sup>7</sup> ibid

<sup>8</sup> Always on Call, Always Concerned, Princess Royal Trust for Carers (2011)

For example, a third of older carers surveyed said that they had cancelled treatment or an operation they needed due to their caring role. This is despite two thirds also having a long term disability or health problem(s) including conditions such as arthritis, heart disease and cancer.

appointments much less to have longer periods of support to care for their own health and recuperation. For example, even when carers are able to access the healthcare they require, there is often insufficient or poorly planned support for their discharge. Carers report a lack of effective planning (or confidence that such planning will happen) on admission and discharge from hospital. One carer who is caring for both her parents needed surgery for her own medical problems but refused because she could not continue to care after surgery. She was deeply concerned that services could not provide the level of care needed to allow her to recuperate.<sup>9</sup>

*“Carers can be discharged from hospital too soon when there is not enough additional or necessary support at home for them to pick up, once again, their caring role immediately following their own hospital discharge from an illness. I was readmitted due to this.”*

Research<sup>10</sup> about carers and their human rights found that carers have delayed emergency medical treatment which could have cost them their life, or put their lives at risk during the course of their treatment.

One carer who was on a drip in hospital was told *“you’ve had your six weeks respite care break this year.”* This example is not unique. Another carer who found she needed lifesaving heart surgery having gone into hospital for a routine procedure, was forced to extend her husband’s stay in residential care by two weeks and was told this would be deducted from her allocation of services for breaks from caring.

*“When I had a heart attack and was rushed to A&E there was no-one I could contact to arrange care for my disabled husband. I had to arrange everything myself by phone. I spent more time in the phone box than I did in my hospital bed.”*

*I became ill overnight. I was haemorrhaging internally and needed immediate hospital admission. I called social services emergency line. In short it took 10 hours to get adequate help organised before I could get myself to hospital. The consultant said I was lucky not to have died.”*

Resources are often inadequate to deliver carers’ right to care for their own health. Services are often not available and therefore although carers have rights, it was difficult to have these rights realised. For example, we heard from carers who are told by a social worker *“have a carer’s assessment done, but there is no money to provide anything”*

Carer’s assessments must deliver outcomes for carers and consider and mitigate the impact of caring on health. This includes ensuring that appropriate services are available to support carers experiencing ill health or disability.

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<sup>9</sup> Whose rights are they anyway? Carers and the Human Rights Act, Carers UK, 2008

<sup>10</sup> *ibid*

We heard from one carer with a serious back problem and was awaiting surgery who was forced to continue to support her daughter to shower after the local authority withdrew the two care staff who had previously provided the help after an assessment said that it was too risky for the health of their backs! The risk to the carer could have been reduced with an adapted shower but waiting lists for adaptations can be considerable – in this carer's case it was a year's wait.

Many GP practices hold a register of carers in their practice and whilst good practice does happen, there is often little link between this register and actual health or social care support for the carer. For example in our recent research<sup>11</sup> three quarters of carers said that their GP knew they are a carer yet 63% said nothing different had happened.

However, some practices are working to support carers, albeit in smaller numbers. Some carers (8%) had been referred on to social services and 12% had had a regular health check. A third said that the practice had arranged for them to have home visits or telephone appointments in recognition of the difficulties they had in attending appointments because of their caring role.

In addition, more attention needs to be paid to ways to ensure that carers are able to take up emergency medical treatment whilst ensuring support is available for the person they care for. Some local authorities in England have a 24 hour emergency helpline to enable staff to look at an emergency plan and put it in place should the carer become ill.

Finally, it is important to recognise that many carers have little or no contact with social care services. We found that 34% of carers were receiving no support at all and 45% had not used any services. Therefore, the role of health along with other statutory and voluntary services in reaching those carers and helping them to access support to help them care for their own health and wellbeing is vital.

## **Carers Scotland March 2014**

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<sup>11</sup> State of Caring, Carers Scotland/Carers UK, 2013