Carers (Scotland) Bill

Fraser MacLean

Over a period of nearly 13 years I provided at-home care and support for both my elderly parents. My mother was eventually diagnosed with Alzheimer’s disease in 2001 but later contracted (and in 2008 died from) cancer - which led to some truly horrific experiences in the days before nursing staff, doctors and consultants working on open NHS wards knew (or even wanted to know) anything about dealing appropriately or compassionately with patients who had dementia (thought of, at that time, as a “social services” disease, since it allowed the NHS to “bump” responsibility for it onto someone else’s budget).

My father suffered from three different kinds of cancer (prostate, skin and bowel) but also had to contend with chronic heart disease, osteoporosis, macular degeneration, partial deafness and Type 2 diabetes. From early 2007 until shortly before his death in 2013 I provided round-the-clock at home care for him which included everything from administrative and bill-paying responsibilities to incontinence care. 2 years after his death I remain unemployed and in serious debt.

I took part in the first ever Carers’ Parliament at Holyrood in October 2012 and was shocked at the lack of media coverage. The morning after the event, instead of finding coverage for this supposedly “historic” gathering on the front pages of The Scotsman, Herald, Mail, Record etc - there was instead a series of headlines about the 2013 Ryder Cup, including some less-than-flattering photographs of the First Minister (in America) waving the trophy over his head.

At moments like that - seeing such an image in place of serious, reasoned press coverage (which Holyrood could and should have sought and encouraged) of the issues raised by Carers during the open debate (and discussion sessions) - it is hard, as a Carer, to feel that much is being done or discussed beyond “window dressing”. I have included here (Page 4) my own contribution to the open debate (Session 1) as I feel strongly that most of the questions I raised then remain unanswered.

Hoping things may change direction for the better soon, with or without the implementation of the proposed Bill,

Fraser MacLean

1. Do you support the Bill?

I support the motivation behind the Bill but am doubtful about much of the wording and seriously concerned about the implementation of the suggested changes and the availability of funds to pursue (let alone achieve) many of the goals outlined in the Bill.
What do you feel would be the benefits of the provisions set out in the Bill?

I would hope that the main benefit would be a continued and open pursuit of realistic policy-making in this area, involving Carers themselves, and an openness to revision of all/any changes outlined in the Bill which, for whatever reason, fail to achieve their stated goals.

How do you feel the Bill could be amended or strengthened?

It could certainly be strengthened, in my view, by providing some indication of how all the suggested changes and improvements are going to be funded and how, over time, that funding is to be sustained.

Is there anything that you would add to the Bill?

Mention is made in the Bill of the negative impact that caring often has on a Carer's career. I believe additional consideration has to be given to the problems faced by Carers, like myself, whose original work (if they have had to curtail or abandon it) involved freelance, rather than full-time, employment.

For a Carer who has been part of a national or international freelance talent pool, moving from job to job with a series of different employers within a particular field, no one employer can realistically be expected to take responsibility for helping either to re-train that former employee or to make a “return” position available to him/her after a prolonged period of non-employment. It would help if the whole issue of re-training for re-entry into the non-full-time employment market, after the death of an elderly relative (for instance), could be addressed or at the very least considered in more detail in the Bill. Similar moves are already underway, in line with European and Scandinavian examples, to help mothers and fathers return to work after raising their young children at home. Comparable provision is urgently required for former Carers.

It is impossible to over-emphasise the degree to which, particularly in care of the elderly, the health of the cared-for person (or people) deteriorates; this, in turn, means that the needs of the Carer change (and usually escalate). Formal assessment of these rapidly-changing needs is often, in my experience, made at intervals which do not necessarily allow for the increasing strain placed, often suddenly, on the Carer by such rapidly-escalating, mutually-aggravating problems and challenges. The Bill needs to address this problem more directly.

The Bill "requires local authorities to establish and maintain an information and advice service for carers" - but what if this information competes or conflicts with the information and advice already available from individual charities, volunteer groups and independent agencies?

So many different agencies and charities already exist - without any official "air traffic control" service to help Carers sift through, compare or even understand the profusion of available information. The result is that, on top of
everything else the Carer has to cope with, THIS massive responsibility ALSO
lands on him or her - responsibility for digging out, ploughing through and then
COMPARING all the available information and advice.

The problem has never been LACK of information, it’s that so MUCH
information is out there, much of it conflicting. Who, ultimately, is the Carer to
trust? Particularly when, as was my experience, once an agency HAS been
identified that CAN help make sense of it all (in my case The Princess Royal
Trust for Carers) THAT agency then goes through a name-change and a
structural shake-down. Carers, at present, would need a full-time secretarial
and administrative staff to help them manage what, at present, is often a
ridiculously confusing landscape of “helpful” information.

The Bill supposedly “places a duty on local authorities to provide support to
carers” - “duty”, yes - but is this not also a burden, both financially and in
administrative terms - and where are those additional resources going to
come from? Again and again as I read trough The Bill, I wondered how on
earth all of this might ever be funded (and monitored). Some degree of clarity
on this point needs, I think, to be added to The Bill.

Repeated mention is made of respite - but “respite” can be rendered almost
meaningless if a Carer’s underlying anxieties persist throughout the “break”
that they are allowed to take from their caring responsibilities; taking “time off”
can simply add to the strain experienced by a Carer because serious
elements of uncertainty are introduced regarding how the cared-for person is
actually being looked after in the Carer’s absence. Even when, for example,
free, non-agency nursing provision can be secured through charities such as
Marie Curie, it takes time and effort (and luck) to reach the point where the
Carer knows and trusts the individual person who is assigned to look after the
cared-for relative in his or her absence. The Bill ought to address this issue.

5 Is there anything that you would remove from the Bill?

Unless it can be made clear WHOM the local authorities will be charging and
how they will be empowered to recover that money, I would remove the
following:

The Bill “makes provision for local authorities to charge for services to carers”

The stated aim of today’s event is to “stimulate debate on the issue of
Services and Support” for Carers. But - beyond the debate itself - what action
and improvement can we hope to set in motion if we don’t, first of all, agree
on our definition of a “carer” and our definition of a “parliament”?

Even with welcome professional support from the available agencies, caring
for people is hard work; Carers, by definition, are workers and the ‘right to
work’ under Article 23 of the Universal Declaration of Human Rights* states
that ‘Everyone has the right to work, to free choice of employment, to just
and favourable conditions of work and to protection against
unemployment’.”
Though “employed” - often around the clock - very few Carers ever chose - freely - to be “employed” in this way and, because we are so often dealing with unforeseen circumstances - that are neither just nor favourable - we have to guess and invent our way through immediate, personal and often distressing challenges and, at the same time, many of us have to wave goodbye to the careers we originally did plan and train for.

I myself spent one year at University, 4 years at Art College, one year in vocational training and then 15 years, working my way up from the shop floor in my chosen profession - only to find myself, at the age of 38, faced with the responsibility of organising, managing and providing care, in all its forms, for a mother with Alzheimer’s disease and a father with cancer.

As they grew older, the “shopping list” of their combined needs grew and became both more urgent and more inescapable. I am now 51, my mother is dead, my father is still alive but requires round-the-clock support and supervision. His savings are gone, my savings are gone, the house we live in has had to be re-mortgaged twice, I have had to cash in my life insurance and, in May of this year, the car we depended on finally had to be towed away for scrap. And, though I now have a wealth of knowledge and experience of all aspects of health provision and social care - away in the distance, lie the smouldering remains of my career.

To qualify for the weekly Carer’s Allowance of £58.45p, a carer must prove, among other things, that he or she is caring for somebody for 35 hours a week. That amounts to £1.67p an hour, less then the minimum minimum wage, for work that is often gruelling and uninterrupted.

Most dictionary definitions of the word “parliament” emphasise the outcomes of debate, the law-making powers of the individuals gathered together. But can we honestly define an event like this as a “parliament” if it is only a once-a-year gathering - and if all of us are not to be present when the resulting legislative powers are exercised?

Please let us do this more often - and let us all work to forge meaningful legislation from meaningful debate.