New Deal for Carers or unfair deal: what is in it for informal carers of stroke survivors?

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Introduction
Proposals for the New Deal for Carers, launched in 2007, include improved access to information via a helpline and carer training. Using informal (unpaid, usually family) stroke carers as an example, we examine research evidence for whether these carers might benefit from the proposals. We argue that too little attention is being paid to the available research and despite some generic carer problems, carer diversity means this poorly targeted input is likely to have little impact. Despite the fact that informal carers save the UK economy enormous sums of money, the budget for the proposals is woefully inadequate. Money might be better spent on increasing uptake of benefits and facilitating primary care to increase support.

Background
Who are carers?
One in 10 of the population (5.2 million people) in England and Wales are informal carers (Census, 2001), and it is estimated that on average they save the economy £15,260 each – approximately £87 billion annually (Carers UK, 2007). Carers frequently suffer as a result of their caring roles and the New Deal for Carers launched in 2007 (Hansard, 2007) is aimed at supporting them.

Carers’ main concerns were reported in a recent survey. Their top priorities included recognition from professionals, income from benefits for carers aged under 65, better services for those they care for, income in retirement and carers’ health and respite breaks (Carers UK, 2008). These findings appear to be an ideal starting point for provision of support.

Stroke carers
Stroke is the single most common cause of severe disability with an estimated 300,000 people in the UK living with moderate or severe disability caused by stroke (DH, 2005). One year post-stroke, approximately one third of stroke survivors are living at home dependent on informal carers (Cassidy and Gray, 1991). Caring for stroke survivors can have enormous impact on carers’ lives (Visser-Meily et al, 2005), and they often feel ill-prepared for a role they have taken on suddenly (McKevitt et al, 2004).
There is a large body of research describing the problems that carers of stroke survivors face but evidence for what influences carer outcomes is inconsistent (Greenwood et al, 2008). Stroke carers, like other carers, are a diverse group with huge variety in social situations, culture and age. Their needs are therefore likely to vary enormously.

**New Deal for Carers (2007)**
The New Deal for Carers has four elements: a review of the 1999 strategy Caring About Carers (DH, 1999) and three practical measures (worth £33 million in total). Money is allocated as follows:

- £25 million for emergency support (short-term, respite at home for crisis or emergency situations)
- £3 million for a helpline, possibly run by the voluntary sector, to provide detailed, up-to-date information. The plan is to provide comprehensive information ranging from national rights and entitlements to what is available in carers’ own areas.
- £5 million for an Expert Carers Programme (ECP) to provide training for carers. The ECP is intended to train carers in advocacy skills and practical instruction (eg, first aid, moving and handling) (Hansard, 2007).

In the Carers UK (2008) survey, carers put respite care as a priority; this will not be discussed here except to mention that given the number of carers and people being cared for, £25 million is clearly inadequate. We will focus on ECPs and information from a helpline as the value of these is more questionable.

**How useful would a helpline be?**
First, uptake is a concern. Carers in general frequently do not recognise themselves as ‘carers’, especially when they first take on the role, which may help to explain why approximately 40-60% of carers’ benefits (worth about £660 million) remains unclaimed (Carers UK, 2006). Such carers are unlikely to contact a helpline if they do not realise it is aimed at them. Increasing awareness of those who are defined as carers and their eligibility for benefits is a priority.

Carers in general would appreciate more information (DH, 1999). A review of the evidence for stroke carers specifically concluded that the effectiveness of information provision had not been ‘conclusively demonstrated’ and that further research was needed to identify these carers’ specific information needs (Forster et al, 2001: 1). For carers of stroke survivors, the information required can be specific to their stroke survivor (eg, prognosis, medication and how to manage their survivor’s specific problems) or general stroke information such as risk factors (Bakas et al, 2002). A helpline could only provide general information.

More research is needed, asking carers specifically what they require for themselves, although any problems identified may not translate directly into
needs with ready solutions. For example, carers may report emotional distress, which may be interpreted by professionals as a need for counselling. However, not all carers believe professional intervention is required, preferring instead to have information on ‘what to expect’ and to rely on their own resources (Mckevitt and Wolfe, 2000: 10).

The evidence suggests that making more information available to stroke carers may do little more than to increase their knowledge, with little impact in terms of their mood, perceptions of their health status or quality of life. Forster et al’s review of the provision of information concluded that focus should be on ‘expressed needs of survivors and carers’ and importantly that ‘the success of such strategies is limited if they are unacceptable to the patient’ (Forster et al: 1, 8).

Overall, bearing in mind the diversity of carers in general and their individual situations, it is hard to see how a helpline could cater for all.

**How useful would an ECP be?**

The main concerns about ECPs relate to targeting the training to specific carers’ needs and carers’ opportunities to attend training. Generally, interventions to support carers of stroke survivors have modest benefits, possibly due in part to insufficient targeting (Visser-Meily et al, 2005). Few studies include training for carers but a recent, successful intervention (Kalra et al, 2004) targeted individual stroke patients and their carers. Standard care was compared with standard care plus training tailored to individuals (e.g., pressure ulcer prevention, lifting and communication). Training was associated with improved outcomes for both carers and survivors (e.g., improved mood and quality of life), emphasising the importance of individualised programmes and suggesting that generic ECPs may have little impact.

The importance of determining whether carers want and are able to attend ECPs must be emphasised. Carers are often unwilling to leave survivors alone at home (Anderson et al, 1995), and if they are ambivalent about training and its value drop-out is likely to be high.

**Conclusions**

Any attempts at supporting carers should be welcomed and carers’ organisations mostly responded positively to the launch of the New Deal for Carers, but concerns remain.

The proposals fail to take into account carer diversity, which has implications in terms of carers’ needs, willingness and ability to engage in ECPs or to contact helplines. Arguably, the proposals are better suited to younger carers who maybe more likely to use helplines and to see more benefits in ECPs.
Evidence that carers of stroke survivors would want or benefit from the proposals is unavailable. Existing evidence suggests they would like specific information and might benefit from individualised training but it seems unlikely that the New Deal would offer sufficiently well-funded, personalised help. All three practical measures in the New Deal are additional to current services but consideration should be given to whether development of existing services such as primary care might represent better value for money and be more acceptable to carers.

The amount of money suggested is totally inadequate. Thirty-three million pounds shared between 5.2 million carers works out at just over £6.00 per carer. Much more is needed. For example, stroke carers are frequently unable to leave survivors alone and the £5 million budget for the ECPs would be inadequate even to fund temporary care allowing carers to attend them. Without this, arguably the group most in need of such support would be excluded. Carers save the economy approximately £87 billion and about £660 million of carer benefits remain uncollected – but only £33 million is being allocated. Hardly a fair deal.

References


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