The need to “carer proof” healthcare decisions
Such decisions may have important effects on family carers; decision making should formally consider them

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Population ageing and fiscal austerity are set to increase the reliance on family carers, who already provide much of the support for people with long term health conditions. Although most carers are willing, providing care can be hugely stressful, affecting mental and physical health 1 and resulting in social isolation and financial hardship. 2 When under strain, carers are less likely to be effective, increasing the risk that the care recipient is admitted to hospital or a care home. 3 Health systems could reduce strain on family carers by routinely considering carers’ needs alongside patients’ needs in everyday healthcare decisions—a concept we term “carer proofing.”

Healthcare interventions (such as a new treatment or a different way of organising care) can affect family carers in various ways (fig 1). Healthcare interventions may reduce the physical demands on carers or make them more (or less) anxious about their loved one’s condition. 3 And some interventions—for example, those that target patient lifestyles—are likely to directly affect the lifestyle of carers too.

Few clinical studies have collected data on both patient and carer outcomes, 3 although this is becoming more common. A recent study of stroke follow-up care unexpectedly showed that the intervention reduced carer depression but did not affect patient outcomes. 4 Conversely, a trial of reminiscence therapy for dementia concluded that though quality of life may have improved for people with dementia who attended the sessions, carers’ anxiety increased significantly. 7 Other interventions, such as the closure of mental health beds or the promotion of activity among frail older people, could also benefit patients at the expense of carers.

From a research point of view, there needs to be a twin focus on collecting more data on the effect of patient interventions on carers and, routinely using these data to inform reviews, meta-analyses, and economic evaluations. This would help to determine the effectiveness and efficiency of interventions more comprehensively. Better evidence would also provide a stronger foundation for carer proofing policy making and clinical decision making. The National Institute for Health and Care Excellence (NICE) already stipulates that economic evaluations of new healthcare interventions should consider carers’ health outcomes as well as patients’. 8 This is rarely done, 9 although recent methodological advances 10 11 ought to support this practice.

At the policy level, how care is organised for people with long term conditions can profoundly affect the lives of carers. The notion of integrated health and care services, for example, holds the hope of reducing the stress that carers experience from lack of joined up care. On the other hand, integrated services might be concentrated on fewer but larger sites, resulting in greater travelling time and less personal service for already stressed family carers.

At the clinical level, guidelines often recommend involving carers in care decisions, where possible. Nonetheless, carers may get squeezed out because of lack of patient consent or busy clinical schedules. If the clinical decision affects the carer, this ought to be taken into account in order to ensure good adherence to the treatment plan. Carer proofing is likely to be particularly valuable at times of change, such as around diagnosis or when someone takes an active caring role. 12

Enhanced carer proofing could complement existing interventions to support carers, such as respite care, carer support groups, and individual education and training. One problem with existing forms of carer support is that the interventions often come too late, with carer stress treated as an inevitable side effect of the patient’s condition. To support carers better,
Carer outcomes should be considered in healthcare decisions for long term conditions from the outset (Table 1). Carer proofing challenges researchers to provide better evidence of the effectiveness and efficiency of interventions from the perspective of all those affected. It also challenges care professionals and policy makers to focus their thinking on how the wellbeing of the patient-carer dyad could be optimised. There is both a moral and a practical imperative to consider carers in healthcare decisions given the vital role they have in supporting the health system.

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### Table

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