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Legacies of caring: the experiences and circumstances of ex-carers

Eithne McLaughlin, BA, MPhil, PhD, and Jane Ritchie, BSc
Department of Sociology and Social Policy, The Queen's University of Belfast, Belfast and Social Community and Planning Research, 35 Northampton Square, London

Correspondence
Dr Eithne McLaughlin
Department of Sociology
and Social Policy
The Queen's University
of Belfast,
Belfast BT7 1NN
UK

Abstract

Although there is extensive literature on carers and their care-giving role, the circumstances of carers after care-giving remains largely uninvestigated. This paper documents the socio-economic and psychological legacies of care-giving among 157 ex-carers who were included in a larger national study of the effectiveness and targeting of social security help to carers, which was carried out in 1989. Therefore, the sample included only those whose care-giving responsibilities had been relatively substantial, that is, over 35 hours a week. Survey data covering the employment status and income levels of these ex-carers are presented, as is in-depth interview material on the psychological and social circumstances of a small group of ex-carers. The article concludes that there are long-term negative financial effects of caring, which the social security system appears to ignore. In addition, the psychological, social and physical health consequences of caring may leave some carers poorly equipped for life after care, a situation which might call for the development of support services in the immediate post-care period. Further investigation of the material and non-material circumstances of ex-carers, preferably on a longitudinal basis, should be a priority in health and social care research. Without such research, our knowledge of the costs of caring borne by individuals, and our assessment of the appropriate contributions that should be made by statutory welfare agencies, remains incomplete. Finally, given the prevalence of informal care-giving, our lack of knowledge of the legacies of care-giving limits our understanding of the causes of income and health inequalities between people approaching pension age and older.

Keywords: community care, costs of care, ex-carers, informal carers

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Introduction

National estimates show that there are about six million people who provide informal care for a dependent person with disabilities, ill health or frailty through age. The 1985 General Household Survey (Green 1988) estimated that one quarter of such carers were providing 20 hours or more of care per week with 15% (850 000) providing 50 hours a week or more. Of those providing the most intensive care, two-thirds are women who are caring for elderly parents, husbands, children, or in a small proportion of cases, other relatives. The remaining third are men who, in a high proportion of cases, are caring for their wives. Although care may be short term, it more often takes place over a long period, with the most intensive input required in the later years. Inevitably, there comes a time when caring responsibilities end, most usually when the dependant dies or moves to residential care.

Although there is extensive literature on carers and their care-giving role (see Parker 1990 for a review), the circumstances of these same people after care-giving has ended remains largely uninvestigated. We know that providing substantial levels of care deeply affects the lives of those who care, materially and non-materially. This suggests that provision of care may have a long-term effect on the lives of those who provided care, and thus attention has been drawn to the possible legacies of care which might result; for example, loss of occupational pensions, loss of former position on a career ladder or mental or physical health difficulties. However, only one study has specifically addressed this issue of legacies of caring. This was an in-depth study by Lewis & Meredith (1988) of 41 daughters, most of whom were single, who had cared for their mothers as co-residents. The study investigated the costs and benefits to the carer, including 'the uncosted outcomes of care' (Ungerson 1987), such as loss of social contacts or poor self-image. Lewis & Meredith found that, for most of the daughters in their study, the legacy of caring was a profoundly ambivalent mix of feelings. On the one side, there were problems and losses; on the other, feelings of satisfaction at having 'done the right thing' and, in some cases, having achieved deeper relationships with their mothers than would otherwise have been the case (Lewis & Meredith 1988; p. 138).

The problems which carers in the Lewis & Meredith study experienced in the post-care period included loss of purpose and identity; loneliness and a lack of companionship; loss of confidence; a sense of lost opportunities; and long-term financial loss. These losses were experienced by almost all the carers in their study, although the extent and seriousness of the problems varied, depending on the degree to which carers had maintained contact with, and had activities in, other areas of life. In a minority of cases, the problems were so extreme as to lead to the conclusion that caring had been 'destructive of self and harmful to physical health and welfare' (Lewis & Meredith 1988; p. 154).

A recent study of people who had claimed the invalid care allowance[1] (ICA) generated both quantitative and qualitative data on the circumstances of ex-carers. Because of the size and nature of the sample from which the data are derived, it is not possible to draw any definitive conclusions about the circumstances of ex-carers in general, since only those ex-carers who had either unsuccessfully claimed or received the invalid care allowance were included. Instead, the purpose of this paper is to consider some of the legacies of care-giving for the carers in this study, both in the light of Lewis & Meredith's work and from a more material perspective than was possible in the Lewis & Meredith (1988) study.

A profile of ex-carers

The evidence presented here arises from research among claimants of the ICA. The study was undertaken in 1989 by the Social Policy Research Unit at the University of York and was commissioned by the Department of Social Security to examine the effectiveness of ICA as an earnings replacement benefit and as income maintenance. The study involved a quantitative national survey of 614 ICA claimants, a qualitative in-depth study amongst a small representative sub-sample (37), and secondary analysis of existing data sources. The survey investigated the circumstances of 288 current ICA recipients, 211 past recipients and 115 unsuccessful claimants. The study used stratified flow and stock samples of applicants for ICA, stratified by the reason for disallowance, or termination of an ICA application or award. Using the Department of Social Security (DSS) ICA Unit's computerized records of all ICA claimants, potential respondants (n = 811) were drawn from a random sample of 35 local social security offices, stratified by region and type of office, to ensure that the different types of area were represented in the proportions that occur nationally. The response rate was 76% (n = 614). The sample was stratified by reason for disallowance, or termination of an award for ICA to ensure that each sub-group would achieve a sample size of at least 50 claimants. Subsequently, the data were weighted to replicate the national proportions of applicants disallowed, or recipients whose awards were terminated, for each of the possible reasons why this may occur, in order to allow generalization to the population of ICA claimants. Analyses were carried out on both unweighted and

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[1] ICA was introduced in 1975 as an earnings replacement benefit for carers providing intensive care (minimum 35 hours a week). The eligibility criteria for the benefit are complex but are conditional upon the person cared for receiving the attendance allowance or the higher or middle rate care component of the disability living allowance. In 1988, when the study was undertaken, 107000 people received ICA, 86% of whom were women. The numbers receiving ICA have since risen to 159324 at the end of 1991 (Department of Social Security 1992).

McLaughlin 1991, Appendix 1 for further technical details).

A significant proportion of the past recipients of ICA had ceased caring since they had stopped receiving ICA. Many of the unsuccessful claimants had also ceased caring since their application for ICA. Therefore, the study yielded a total unweighted sub-sample of 157 ex-carers and a weighted sub-sample of 214 ex-carers whose caring responsibilities had ended 3–12 months previously. Most, about three-quarters of the unweighted sample, had previously been recipients of ICA and almost all (92%) were women (see Table 1). Three-quarters of the unweighted sample were still married or cohabiting, 18% had previously been married and 7% had never married.

As Table 1 shows, these ex-carers had previously provided high levels of care over long periods to close relatives usually as co-residents. Just under three-quarters had been co-resident carers. Over two-thirds (72%) had cared for an elderly parent or parent-in-law, 17% for a spouse, 8% for a child and 3% for a more distant relative or non-relative. Forty-eight per cent had been care-givers for at least 5 years, 18% for more than 10 years, and a further 40% for between 1 and 5 years. Two-thirds had provided at least 50 hours of care per week, and 94% at least 35 hours per week. In half of the cases, the caring relationship had ended with the death of the cared-for person; in a quarter the cared-for person had moved into residential care. Seventy per cent of ex-carers were aged 45 or over, and nearly half (43%) were aged 55 or over (Table 1), reflecting the long periods of care-giving in which they had been engaged.

The qualitative study, carried out shortly after the main survey, was designed to explore the experiences and circumstances of ICA claimants in greater depth. The sub-sample contained 10 ex-carers, all of whom were women who had previously received ICA. Seven had been caring for elderly parents, one for grandparents and the other two for a son or daughter. Six of them were co-resident when caring. In all cases, care responsibilties had existed for two or more years and for half had been much longer term. The amount of care provided varied from 35 hours (for a dependant living in another household) to over 100 hours a week; around half provided intensive care of 50 hours or more. Caring had ceased at the death of the dependant (6), because they were in hospital (2) or because they were in residential care (1). In one case, the daughter who had been cared for by her mother had married and was now cared for by her husband. For all the carers, an interval of at least 6 months had passed since their caring responsibilities had ended and for some the post-care period had been about a year.

The after effects of care

The survey analysis of the circumstances of ex-carers in this study suggested that there are important negative financial consequences following the provision of high levels of care over a period of years; a subject discussed in detail later. In the qualitative study, ex-carers described the impact of these consequences in some detail and also identified other significant after-effects of their caring role which mirrored those described in the Lewis & Meredith (1988) study. Most carers were affected negatively. Some of the feelings or experiences noted were seen as relatively minor and transient. Others were of a more serious nature with perceived lasting or damaging effects. Because of the focus of this study, the financial effects of caring, and particularly those arising from withdrawal from employment, were noted most commonly. Other effects had also taken a major toll on some ex-carers lives, and these were sometimes related to the adverse material effects of caring.

Lewis & Meredith (1988) identified three types of coping responses within which women fitted caring into their everyday lives. These were represented as a balancing act, integration and immersion. The balancers, who had attempted to combine employment and other activities with caring, experienced fewer negative legacies of caring in the post-care period. The balancing act these carers had to perform brought stresses and strains while caring, and external activities were also difficult but provided alternative sources of identity and purpose to fill the gap in the post-caring period (Lewis & Meredith 1988; p. 115). In contrast, those who had immersed themselves in caring, and invested their identity heavily in it, experienced more problems in adjusting to the end of care. This brought severe loss of identity, purpose and confidence. For those who managed to integrate caring, the role appeared to give a purpose to life rather than exert conflicting demands. In certain respects, the caring experience for this group was less stressful and more satisfying than for other groups.

There was evidence from the qualitative study to suggest that these three types of response existed among the ICA ex-carers, even though their circumstnaces were, in some respects, quite different from the ex-carers in the Lewis & Meredith study. For example, all but one of the ICA ex-carers were married, seven had children still living at home while they were caring, and only six out of the ten had been co-resident carers. The distinction between balancers and integrators, however, was not always clear. We found a more simple immerser or non-immerser distinction was empirically more suited to the data.

Table 1 Profile of the characteristics and circumstances of ex-carers in the 1989 ICA study

	Unweighted data			Data weighted by national values
	Past ICA recipients (%)	Unsuccessful claimants (%)	All (%)	All (%)
Sex				
Men	5	20	8	4
Women	95	80	92	96
Total number	121	35	156	214
Marital status				
Married cohabiting	79	60	75	78
Single	7	9	7	4
Ex-married	14	32	18	18
Total number	121	35	156	214
Age				
up to 44	31	31	31	30
45–54	29	20	27	25
55–pension age	26	34	28	29
pension age +	16	14	15	16
Total number	121	35	156	214
Relationship				
Spouse	14	26	17	18
Parent	76	59	72	66
Other relative	10	15	11	16
Total number	107	34	141	214
Co-resident care				
Co-resident	71	77	73	76
Separate households	29	23	27	24
Total number	122	35	157	214
Length of care				
<1 year	6	37	13	14
1–5 years	43	32	40	25
5–10 years	33	17	30	45
10+ years	18	15	18	16
Total number	121	35	156	214
Amount of care per week				
<35 hours	5	6	6	4
35–50 hours	24	27	25	26
50+ hours	67	64	66	68
>35 hours, variable per week	4	—	3	2
Total number	120	33	153	207
Reasons for end of care				
Residential care	30	9	25	10
Other carer	11	3	9	4
Temporarily in hospital	4	3	4	4
Died	44	74	51	75
Other	11	11	11	7
Total number	122	35	157	214

Five of the ex-carers in the qualitative study fell into the category of immersers and five into the category of non-immersers. This division provided a useful context within which to consider the different types of after-effects of care that were reported.

The psychological after-effects

Ex-carers experienced a variety of emotions in the post-care period. For those whose dependants had died, there was often an intense initial feeling of loss. The natural feelings of grief arising from the death of a parent or child were compounded by the intensity of the care that had been given. For many, these feelings of personal loss were deepened by the void now left in the carers' lives. All the ex-carers in the study had provided high levels of intensive care to the people they cared for.

Mrs Blackwell was 55 when she started caring for her mother. In the last year before her mother died, the personal care required became highly intensive. Mrs Blackwell's mother had died about 9 months before interview and she was still trying to adjust to her new circumstances:

> I haven't got the inclination at the moment to do anything . . . if I found a little job then I would take it, yes I would . . . well you can't keep going out around the shops, if one came along, but you can't find them today really . . . I just keep doing housework . . . I keep going over and over it, jobs that don't need doing. When you are looking after them . . . I would get up at half six or seven, I would have a cup of tea and then get her washed, get her dressed, then another pot of tea, then she would go in here and she would be there for the day. (Co-resident immerser).

Mrs Blackwell was now 62 and felt it unlikely she would ever get work to provide the occupation she now so needed. Some carers saw work as one way of filling the gap and a few argued that it was important for this reason to have continued some employment while caring.

For some carers, the loss of the caring role had been accompanied by considerable relief now that their dependant was no longer in pain or distress or that they did not have as many demands placed on them:

> When I look back over all the years I gave her care, I don't regret one bit of it for all you didn't get anything for doing it, I don't regret it at all . . . [it has made] an awful lot of difference [since caring ended] . . . not having to go to bed at night dreading . . . waking up in the morning and thinking 'Oh I hope she feels a bit better today or she's not irritable and always saying I wish I could die' and things like that; which is very upsetting when somebody you love keeps saying 'Oh I wish I could die and why am I like this' and it's taken a huge, huge burden off my shoulders, it really has . . . it's not until the person dies and you look back that you realize how much . . . your whole life is geared around that person that's sick and it's not until they die that you realize how much it is. (Non co-resident — non-immerser).

The demands of caring described by this carer were noted by many others. However, some found the effects of such demands continued long after the post-care period. There were people who felt considerable anxiety or stress in the post-care period, which seemed only to surface after their caring role had ended:

> Probably nerves, I don't know what it is . . . I get terribly down and depressed I think it is all to do with, it is really only affecting me now . . . you see at the time, what I think happens is when you are actually doing the things, all those years, I knew I had to do it, it's as simple as that, you are concentrating on that all the time . . . I knew I had to do it, it didn't affect me then because I had to keep going even when, as I say, I was ill, I knew I had to keep doing it; so I think in my case it has affected me all the more since she died, it's only since then it has hit me. (Co-resident, immerser).

A second consequence of the demands of caring can be a loss of confidence or self-esteem, which also carried over into the post-care period. It is clearly exacerbated by the disengagement from employment activity but also diminished social contact:

> You do lose confidence, because like I said . . . you get that you can't mix and you are used to talking to old people. Now my mother used to fall asleep a lot and you daren't move in case you woke her up and I used to sit just staring . . .' (Co-resident, immerser).

> You do get very stale I think looking after somebody . . . you tend to think that you're not worth very much because you're doing this . . . I know all jobs have their drawbacks but they're [friends] telling you what they're doing at work and you think here I am, all I'm doing is sort of, looking after somebody all the time and it's very monotonous and repetitive . . .' (Non co-resident — non-immerser).

The social consequences

The impact of caring on social contact and activity was noted by many carers, in this, as in other studies. It was seen to be caused by the practical demands of caring, disengagement from employment, reduced income, loss of personal confidence, all of which had greatest effect at the time of caring. Social activity did not immediately resume when the caring came to an end. Some people's social networks had become too fractured, or they had lost the habit of socializing. Other people had continuing financial difficulties:

> Most of our friends don't live here now, all of our good friends have all moved away, and we don't get to see them very often (a) because of looking after mother and (b) because of the cost again. (Co-resident, immerser).

> I never see anybody from one end of the week to the other really. . . . I suppose probably that is why I get so depressed, every now and again that is how it affects me . . . it would have helped to have a break . . . we were tied to the house all the time . . . I would go to the shop each day for a few bits and do my weekly shopping and that was my most time out of the house. (Co-resident, immerser)

> It's very rare I see them [friends] now . . . at first you see them in the village and you talk and at first I used to get to go out on a Saturday night. You just can't afford it after a while . . . I feel if I can't pay, I won't go out . . . . (Non co-resident, immerser).

Health

Several carers in the ICA study said they suffered from physical health problems as a result of caring. The most frequently cited were back problems caused by regular lifting. Another commonly mentioned problem was physical tiredness or exhaustion, the result of the constant physical and psychological demands arising from the caring role. The removal of these demands meant that in the post-care period some of the carers found their health recovering. The opportunity to have unbroken sleep, the break from physical tasks and the removal of anxiety or worry about the dependant, allowed recuperation to occur in some cases.

Others found that their health problems continued or even started after the caring ended. The carer cited previously said her psychological distress had not really surfaced until her mother had died. Some carers felt that they could not allow themselves to be ill while they were in the caring role. Certainly some of the ex-carers had suffered from health problems whilst caring which had not received the attention or treatment they should have had. One woman, for example, had had a bad attack of influenza, which she had almost ignored because of her caring responsibilities. She said she had never really been well since that time. Another had suffered with a back problem and should not have done any heavy lifting. She could not avoid doing some and so the back problem had persisted.

It was clear that some of the health problems experienced in the post-care period were reactions to the strain that the carers had been under. Where nothing replaced that pressure, ex-carers health, particularly their mental health, could be at risk. Lewis & Meredith (1988) found this was the case for a number of the ex-carers who had immersed themselves in the caring role to the exclusion of almost all contact with the outside world.

The psychological, social and physical consequences of caring were not areas of primary focus for the ICA study. Where they were mentioned, however, it was clear that people's lives had been quite deeply marked. The results were very similar to those identified by Lewis & Meredith (1988), who also identified lost opportunities. These related to personal circumstances such as not getting married, not having children or more children, lack of personal growth, and lost employment opportunities with the attendant long term financial loss. The loss of purpose and identity, a loss of personal confidence and the loneliness brought about through disengagement from external activities are all highly evident in the psychological and social consequences described. There is also evidence to suggest, tentatively, that the ex-carers who noticed greatest deleterious effects in these terms were those who had immersed themselves in the caring role. Certainly, the more extreme cases of loss of identity or confidence and loneliness were found amongst the immersing carers.

Income

The ICA study provided the opportunity for a detailed analysis of the income levels and employment activity of carers and ex-carers. This study, like most other studies of informal carers, identified reduced income while caring resulting from lowered or no participation in employment. The carers surveyed had lower than average personal and household incomes and low incomes continued in the post-caring period. Age, lack of employment and early retirement without the benefit of occupational pensions, combined to make the personal and household incomes of ex-carers low. They were even lower than those of carers in the study, although, with the absence of the disabled person, the expenditure needs of ex-carers were probably not as high as those of carers.

Analysis of weighted data showed that ex-carers net household incomes were just over £50 per week per capita. In contrast, the average disposable income per capita in the whole population was £92 in the 1988 Family Expenditure Survey (FES) (Table 2). Among ex-carers under pension age, the difference between their household incomes and comparable households in the general population was very large – for example, £141 per week for two-adult households compared with £292 in the general population (Table 3). These data are not conclusive, as the 1989 ICA study sample is not directly comparable with FES, a general population survey. Some of this difference may be a result of the greater heterogenity among two-adult households in the general population. These households would include both younger couples without children, where both partners are

Table 2 Comparison of household size and disposable household income, 1988 Family Expenditure Survey, and net household income, 1989 ICA Survey: ex-carers, £ per week, (number, weighted data)

	Average household size	Average household income, £	Per cap £
1988 FES, UK	2.52	233.20	92.54
ICA Survey ex-carers			
Past ICA recipients	2.75 (166)	146.41 (101)	53.24
Unsuccessful claimants of ICA	2.75 (46)	143.92 (28)	52.33

Source: FES (1988), HMSO (1990) and McLaughlin (1991).

likely to be employed, and older couples whose children have left home and where the probability of employment among the female partners is lower than for the younger couples. Nevertheless, some of the difference between the two-adult ex-carer households in the ICA study and the whole population of two-adult households in the FES almost certainly represents the legacy of informal caring, as distinct from the legacy of childrearing. Ex-carers over pension age in this study, on the other hand, had income levels not too dissimilar to those of other retired people in the general population. The ex-carers in this study had low personal incomes (Table 4), particularly past recipients of ICA whose mean personal incomes were £45 a week compared with £69 a week for ex-carers who had unsuccessfully claimed ICA.

Comparison of the incomes of carers and ex-carers in this sample suggest that ex-carers who were receiving ICA while caring are likely to see a drop in their personal, and, to a lesser extent, household, incomes after caring ends (Table 5). In most cases, the loss of disability and carer benefits at the end of care had not been replaced with income from employment, at least in the first year after caring had ended.

The carers and ex-carers in the ICA study felt that the difficulty of achieving financial recovery after caring ends should be recognized by benefits, such as ICA, continuing to be paid for an interim period. Since the study was undertaken, some policy change has occurred in this area, and this is explored further in the concluding section. Although the demands for this were usually quite modest, most commonly in terms of a few months or even weeks, the need to recognize a period of adjustment was a clearly stated principle:

> I think they should at least give you another month . . . You're looking after them so you can't work, but if they'd been working they'd have given a month's notice and they'd have time to adjust to not having this wage . . . I think they should let you have it for a month, either after they die or go into care, to give you time to adjust . . . Like when my mum died, I had to run all over the place which was costing me money and I didn't have that £23.76 [ICA] then. So I lost

Table 3 Disposable household income, 1988 Family Expenditure Survey, and net household incomes of ex-carers in the ICA Survey, £ per week, by selected household composition types (number, weighted data)

	1988 FES	1989 ICA Survey: ex-carers		
	Mean (£)	All Mean (£)	Past ICA recipients Mean (£)	Unsuccessful claimants Mean (£)
Non-retired households				
Without children				
Two adults	292 (1423)	141 (41)	148 (34)	110 (7)
Three adults	352 (442)	171 (23)	168 (21)	208 (2)
With children				
Two adults, one child	276 (578)	199 (7)	211 (6)	— (1)
Two adults, two children	295 (897)	127 (13)	102 (10)	211 (3)
Retired households				
One adult	80 (1012)	120 (13)	102 (9)	174 (4)
Two adults	151 (727)	133 (14)	133 (14)	—

Source: Table 4.12 McLaughlin (1991).

Table 4 Mean personal and household incomes (per equivalent single adult) of ex-carers, £ per week, (number, weighted data)

	Personal	Household
Past ICA recipients	45 (140)	82 (101)
Range	5–185	25–215
Unsuccessful claimants	69 (45)	84 (28)
Range	5–165	25–215
Non-response:		
Past recipients	(27)	(66)
Unsuccessful claimants	(1)	(18)

Source: Table 4.13 McLaughlin (1991).

> £23.76 up to my mum's funeral . . . if they'd left even a week it would have paid your bus fares or taxis or whatever. They stop everything then, don't they, after they're dead. (Non co-resident — non-immerser).

Others, especially those who had foregone promotion opportunities, or retired early, with serious consequences for occupational pension rights, felt that there should be some equivalent of occupational pensions for informal carers payable to ex-carers by the state.

Employment

The low incomes of ex-carers in the 1988 ICA study were primarily because of low levels of employment amongst those under pension age after caring had ended. A number of studies (see Parker 1990 for a review) had identified a depressing effect of caring responsibilities on the level and nature of the labour force participation of carers. Most recently both the 1985 GHS (Green 1988) and the 1985 OPCS Disability Surveys (Martin & White 1988) have documented lower levels of employment among carers than in the general population, an effect which increases as caring responsibilities increase. The adverse effect of caring on employment appears to occur above 20 hours of care per week, and takes two forms; reduction of the employment rate and increases in the proportion working part-time rather than full-time. In the 1985 GHS, a third of the total population under pension age were not employed compared with two-thirds of those under pension age and providing 50 or more hours of care per week (Table 6).

Past recipients and unsuccessful claimants of ICA who were still caring for a disabled person showed similar levels of participation to those providing similarly high levels of care in the 1985 GHS. Only 4% of carers receiving ICA were employed. At the time of the study in 1989, carers could only earn up to £12 a week while receiving ICA (after allowances against substitute care costs, although none of the carers knew that the earnings limit could exclude substitute care costs). The current limit is £50 a week.

The effects of caring on employment, and of ICA receipt on employment, continued into the post-caring period. Most ex-carers had not found employment in the 3- to 12-month period since caring had ended. Two thirds of the ex-carers who had received ICA while caring, and half of those who had not, were not employed (Table 7).

Those who had received ICA when they were caring were least likely to be employed after caring had ended. Thus high levels of withdrawal from paid work when caring are associated with low levels of employment after care-giving has ended. Those in their late middle-age when caring ended, clearly faced particular problems in attempting to return to

Table 5 Carers and ex-carers personal and household incomes, 1989 ICA Survey, £ net per week, (number, weighted data)

	Personal income		Household income per single adult[1]	
	Carers	Ex-carers	Carers	Ex-carers
Current ICA recipients	55 (258)		86 (196)	
Range	23–165		10–235	
Past ICA recipients		45 (140)		82 (101)
Range		5–185		25–215
Unsuccessful claimants	35 (59)	69 (45)	69 (40)	84 (28)
Range	5–185	5–165	10–155	25–215

[1] Using McClemens equivalence scales.

Source: Table 4.14 McLaughlin (1991).

Table 6 Employment status by amount of care provided, General Household Survey (1985), %

	Amount of care per week				General population 1985 GHS*
	All carers (%)	Less than 20 hours (%)	20 to 49 hours (%)	50+ hours (%)	(%)
Working full-time	44	48	36	21	52
Working part-time	20	20	22	12	15
Not working	36	32	42	67	33
Total:**	1827	1467	180	180	

*Source: Table 2.9 Green (1988) and Table 3.2 McLaughlin (1991).
**Total = 1827 present carers, under pension age.

Table 7 Employment status of ex-carers under pension age, by age, 1989 ICA Survey, %, weighted data

	Under 40 (%)	40 to 49 (%)	50 to pension age (%)	All (%)
Past recipients of ICA				
Employed full-time	7	18	1	7
Employed part-time	61	20	23	29
Not employed	32	62	76	64
Total number	27	40	74	140
Unsuccessful claimants:				
Employed full-time	31	22	35	30
Employed part-time	38	24	16	23
Not employed	31	54	49	46
Total number	10	11	20	41
All				
Employed				40
Not employed				60
Total number				181

Source: Table 3.8 McLaughlin (1991).

Table 8 Employment rates of older people, 1984, Labour Force Survey, %

	50–54		55–59		60–64
	Men	Women	Men	Women	Men
Employed	80	62	74	48	52
Not employed	20	38	26	52	48

Source: Dale and Bamford (1988). Reproduced by kind permission of *Ageing and Society*.

employment. A third of ex-carers who had received ICA and were aged under 40 were not employed, two-thirds of those aged 40–49 and three-quarters of those aged between 50 and pension age (Table 7).

Although employment rates generally decrease with age, the employment rates of both younger and older ex-carers in the 1989 ICA study were low compared with those of the general population (Table 8). The 1985 GHS also collected some information on people who had been care-giving in the previous 12 months. Those ex-carers who were under 50 at the time of interview had very similar employment rates to non-carers; but amongst those aged between 50 and pension age, ex-carers had lower employment rates than non-carers (Table 9).

The most common reason for difficulty in returning to paid employment was age. A high proportion of ex-carers were in their late forties or early fifties when their caring responsibilities ended. They felt their chances of getting work were low,

Table 9 Employment status of ex-carers* and non-carers** by age, 1985 General Household Survey, %

	Ex-carers		Non-carers	
Employment status	<50 (%)	50 to pension age (%)	<50 (%)	50 to pension age (%)
Employed	71	57	71	63
Not employed	29	43	29	37
Total number	294	112	9213	2459

*'ex-carers': people not providing care at time of interview but who had been care givers in preceding 12 months.
**'non-carers': people not providing care at time of interview and who had not been care givers in preceding 12 months.
Source: Table 3.10 McLaughlin (1991).

either because employers were not interested in employing women of that age or because the competition from younger women returners was too strong. Even if they themselves had already returned to employment after caring for children, they still saw themselves as disadvantaged having had a subsequent break to care. The following case is illustrative of this.

Mrs Roberts was 52, divorced and had lived on her own since her children left home. She received income support and housing benefit. Her mother, in a nursing home at the time of interview, suffered from arthritis and angina and had been housebound for several years. Mrs Roberts provided care for her mother while she had lived in her own home. When she first starting looking after her mother, she worked part-time doing bar work, a job she had successfully combined with her own family responsibilities when her children were at home. As her caring responsibilities grew it became impossible to continue work and she gave up her job in 1983. Despite attempts to get work over the last 9 months, she now felt her age would make it difficult to find a suitable job:

> With being 52 I can't get work now . . . I'm looking for a full-time job. I must have full-time for bills . . . I've been offered 12 hours or 15 hours but that's no good – they're only offering you £2.00 per hour . . . I was only in my mid-forties [when she gave up work] and now I'm 52 and you see in the paper 'up to age 45 apply' . . . the work I was in . . . it's only young girls they take now and I don't think they will take older ones on. (Non co-resident, immerser).

A number of the ex-carers were conscious that they no longer had the appropriate skills or experience to re-enter the labour market. For some, this was because of technological advances, in areas such as secretarial or clerical work. For others, it was a fear that their loss of experience in a professional or vocational job would place them at a disadvantage in moving back to their previous occupation.

> I was working in an office [before daughter was born] and I was sort of registrar of stocks and shares for a fairly small company in Salisbury . . . it was a very responsible job and I was earning good money . . . I could never go back . . . I probably would not have the confidence to be honest, not now . . . I'm sure it [caring] must affect your chances. When I did work, if you could have seen the computer room, it was a joke. Their computer, which most probably now condenses into something like a tape recorder, was as big as this room. It was at the very beginning of computers when I left work. I haven't a clue about that side of it at all. I don't know anything about word processors, the typewriter they have got there [in present job] is the most modern thing they have got.' (Co-resident, immerser).

Underpinning anxieties about both age and skills was a clear loss of confidence amongst some women. Its effects on re-entering the labour market or returning to an original career could be marked. The physical and psychological strain of caring, which had taken a toll on the health of some ex-carers, prevented an immediate return to work for some women. In addition, a particular problem exists for carers who are uncertain about the continuation of their caring role. For example, a cared-for person might go into hospital initially for a temporary period, but hospitalization is continued for several months.

One of the ex-carers in the qualitative study was in exactly this situation. She was in her mid-40s and had been caring for her father. It now seemed that her father, whose condition had deteriorated, would remain in hospital, but no one could give any guarantees about this. As a consequence, the carer was in a dilemma about future employment. She had had a small part-time job as a secretary while her father lived with them, but now wanted to return to secretarial teaching which she also used to do. She had had a job offer but, because of uncertainty over her father, she was not sure whether she should take it:

> I am wondering what to do, it is the situation of my father hanging over me and I don't know what to do, take it or not, I don't want to take something on and let them down, it is difficult (Co-resident, non-immerser).

Among the ten ex-carers interviewed in depth, three had returned to employment in the post-care period. A further two had had some employment whilst caring and had continued to work. All of them were part-time, either in clerical work, unskilled domestic service work, or residential care. All but one of those who worked in the post-care period were non-immersers.

For those who returned to employment the benefits of working again were highly valued:

> I'm a bar maid now . . . I'm on £2.50 an hour . . . the hours (12) I've got now suit me. I don't need the money 'cos after his [husband's] accident he got quite a bit of money [over £20 000 compensation] which was last July . . . I don't need the money now but I need something to do. After looking after mum for 3 years I find that I've nothing — I don't feel sorry for myself but I'm stuck here all day . . . so I have my little job just to get me out of the house . . . it's meeting other people more than anything . . . being a bar maid is one of the best jobs for that, for meeting other people. Otherwise I think I'd just crack up . . . (Non-co-resident, non-immerser).

One of the people who had taken up employment since caring ended was someone who had clearly deeply immersed herself in the caring role. She had cared for her daughter, who suffered brain damage as a small baby, until she died at the age of 15. She had experienced a loss of confidence, health problems resulting from providing 24-hour care and an overwhelming sense of loss in the post-care period. Friends and family had persuaded her to get a job and she now worked part-time as a secretary in a school. Although the job was of a rather different nature from her pre-caring employment, she felt she would not have the confidence to go back to her previous kind of work. She nevertheless found re-engagement in some kind of employment activity beneficial:

> I work in a school, a little private school, as a secretary. There is only one day a week available, because the other secretary does 4 days. But I like it . . . I would [do more] if there was more than one day. I have also catalogued their library which has given me another couple of days here and there to do . . . everybody thought it would be good for me to get back to work. I can't stay in the house too long. I can't see the point of walking around here crying all day. (Co-resident — immerser).

The evidence suggests that the effects of intensive caring on employment activity are likely to continue long after caring ends. The difficulties people face are likely to heighten as the period of care increases. There is a double penalty for carers in terms of labour market participation. The more years they give to caring, the lower their chances of regaining the employment activity or occupational status they might once have had.

The legacies of caring

This article has shown that the consequences of providing intensive informal care for a dependant can continue well into the post-care period. For some people, and particularly younger carers, the effects may be short lived. For others, the impact of caring will be permanent. A few general conclusions can be drawn.

It is clear that the after effects of care are related to the intensity of care, and the length of the period over which it continues. All those who had provided high levels of care, for 50 hours or more a week, over a period of years, were left with some long-term negative consequences.

The ICA study data has highlighted the long-term income and employment effects of caring which continued into the post-caring period. Low employments levels after a substantial period of intensive care-giving, particularly among older ex-carers, resulted in low personal and household incomes. Carers who had continued to work while caring clearly had better options for employment after caring had ended. In this respect it is important to note that the almost total lack of employment of carers receiving ICA was only in part a result of the depressing effect of caring on employment. It was also a consequence of the low level of the earnings limit set for ICA, £12 a week at the time of the study. This greatly restricted the types of part-time work that could be undertaken by those carers who could otherwise have combined working and caring. This effective bar from most forms of employment whilst caring contributed to the difficulties of returning to employment after caring ended, and hence promoted dependence on benefits.

Policies which would facilitate greater participation in some paid work could therefore enhance the situation of carers after caring has ended. It is encouraging to note that the earnings limit for ICA in 1993 was £50 a week. However, measures to support the combination of employment and informal care-giving through the development of employment-related measures, such as rights to paid and unpaid leave, or rights to request part-time hours, and further development of substitute care services, are required.

There will always be some carers who, because of the nature of the cared-for person's needs or the absence of substitute care from informal or formal sources, will not be able to combine any paid work with care-giving and their long-term financial needs remain to be addressed. The financial consequences for people who have cared for prolonged periods seem, in the long term, quite bleak. Not only will they live on lowered incomes whilst caring, but their potential earning capacity after caring will be greatly reduced. Even if they do return to some employment their job prospects will be low because of loss of skills, careers or occupational moves. Moreover, their opportunities to save money or to accrue pension entitlement will have been greatly reduced. It is in these financial circumstances that many long-term carers will find themselves in their fifties as they move towards pensionable age. This must surely raise questions about their financial prospects in retirement and older age.

Carer's disengagement from employment has significant effects on other aspects of the post-care experience. The loss of confidence and lack of social contact which ex-carers experience are exacerbated by withdrawal from paid work while caring. Carers' physical and psychological resources may also become depleted through the nature of the caring role itself, and recovery will almost certainly not be immediate. People might be poorly equipped for life after care. Some of these burdens might have been alleviated by the provision of more effective substitute and respite care services during the care period; and by more appropriate and timely professional counselling as Lewis & Meredith (1988) conclude. They might also be helped by the intervention of some support services in the immediate post-care period.

It might seem premature to suggest specific policy changes to help ex-carers since there is relatively little information available about them. We have confirmed Lewis & Meredith's (1988) findings of the difficulties ex-carers face and for which they seemed largely unprepared. We have documented a substantial long-term negative financial effect of caring. We feel it legitimate to conclude that, from a carer's perspective, the provisions of the social security system in particular must seem inadequate. Not only are carer benefits (with the exception of the carer premium in income support, see below) withdrawn the moment caring stops, but there is no recognition of the need for any long term compensation. Although in the appropriate circumstances they will be able to draw income support, they will have lost any right to unemployment benefit. Unless carers are over pension age and are entitled to a state pension, they will have nothing in the short term to replace the disability or care benefits they have lost. The principle so clearly expressed by ex-carers in this study, that the social security system should acknowledge the legitimate need of carers for a period of adjustment after care-giving has ended, has been partially recognized in social security policy. The carers premium of £10 a week under income support, payable to those in receipt of both income support and ICA, which was introduced in October 1991, continues to be paid for 8 weeks after the death of the cared-for person. Whilst this is an important development, it is regrettable that ICA itself is not paid after caring ends for at least a short time. The carers premium is only paid after caring ends if the cared-for person has died, resulting in disadvantage for those carers whose dependent relatives have moved into residential care, often for a very short period towards the end of their lives. This, together with ex-ICA recipients ineligibility for unemployment benefit, and the lack of recognition of the long-term material impact of high levels of care-giving over an extended period must seem poor reward for having devoted several years to 'community care'.

Further study is required of the material and non-material circumstances of ex-carers, preferably on a longitudinal basis. Without such information, our knowledge of the costs of caring borne by individuals, and our assessment of the appropriate contribution the State should make, is incomplete. Until more is known about their circumstances, and policy attention turned towards them, too many ex-carers will be left with large negative legacies as a result of their pivotal role in community care. Given the prevalence of informal care-giving in contemporary society, lack of knowledge as to how care-giving affects the long-term, and post-care, financial, employment and non-material aspects of people's lives, will limit our understanding of the causes of income and other forms of inequality between people approching pension age and beyond.

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