



# The needs of carers who push wheelchairs

Needs of carers  
who push  
wheelchairs

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## Abstract

**Purpose** – The purpose of this paper is to establish the outcome of wheelchair prescription procedures for carers supporting a wheelchair user with special reference to their health and well-being.

**Design/methodology/approach** – A postal questionnaire was used in conjunction with analysis of policy and practice documents in wheelchair prescription and carers' needs.

**Findings** – The majority of carers reported a wide range of health problems. A relationship between wheel chair type and reported carer pain was noted. Only a minority of carers considered that they had received an adequate carer's assessment, and few had received training in wheel chair management; such training where it had been carried out, led to reduced reports of pain.

**Research limitations/implications** – The study invites more detailed analysis of both the conditions under which wheelchair prescribing takes place and the impact of assessment and training on carers' health. The study is based on a relatively small, local sample and a more extensive study is called for.

**Practical implications** – Procedures for prescription of wheelchairs should be reviewed and steps taken to ensure that adequate consideration is given to the health needs of carers and the circumstances under which they will push the wheelchair.

**Social implications** – More thoughtful prescription of wheelchairs will lead to increased health of carers improving their quality of life and reduce demands on health services and the accompanying risk to their capacity to carry on caring.

**Originality/value** – The study addresses a neglected topic, which clearly identifies the consequences of inadequate prescription of wheelchairs for the health of carers, a topic generally neglected in the literature.

**Keywords** Wheelchairs, Carers, Carer assessment, Carer health, Wheelchair prescription, Carer training

**Paper type** Research paper



## 1. Introduction

Unpaid carers in Scotland, as elsewhere in the UK, represent a key resource in supporting individuals with limited physical or mental abilities. There are approximately 657,300 unpaid carers in Scotland (about 13 per cent or 1 in 8 of the population), typically but not

invariably a family member. Of these, 79 per cent were sole carers in their household, while 48 per cent provided 'continuous care (Stewart and Patterson, 2010). The same authors report that the delivery of such care is prolonged, with 70 per cent providing support for over five years. A majority of these, 69 per cent, are over the age of 50 years, with age-related changes presenting increasing obstacles to care giving. Within the region in which the present research was undertaken, Fife in the east of Scotland, these figures are closely replicated (Office for Public Management, 2006), with a majority of carers over the age of 50 years and 70 per cent spending 50 hours or more per week caring.

Although difficult to calculate, the economic value of carers to society as a whole is considerable: Carers UK estimate the economic contribution of unpaid carers to be £87 billion each year, equal to the entire budget of the NHS (Buckner and Yeandle, 2007). Extrapolated to Scotland, the economic contribution of unpaid carers is approximately £7.25 billion each year.

The contribution of carers is well recognised in Scottish legislation and policy. The Community Care and Health (Scotland) Act (2002) gives all unpaid 'substantial and regular' carers a legal right to a carers' assessment, placing on local authorities the duty to inform carers of this right and to take account of the care they provide, their views and those of the person in need, before deciding what services to provide. It also gives Scottish Government ministers the power to require NHS Boards to draw up carer information strategies for informing carers of their rights under the new legislation. This was implemented in 2006 in the Scottish Executive's *NHS Carer Information Strategies: Minimum Requirements and Guidance on Implementation* (Scottish Government, 2006a), which outlines requirements on boards to ensure that:

- staff identify carers;
- provide them with targeted information, including their right to a carers' assessment, and, as a minimum; and
- signpost them to relevant services.

The headline message of the *Carers Strategy for Scotland 2010-2015* (Scottish Government, 2010a) is:

Carers are equal partners in the planning and delivery of care and support. There is a strong case based on human rights, economic, efficiency and quality of care grounds for supporting carers. Without the valuable contribution of Scotland's carers, the health and social care system would not be sustained. Activity should focus on identifying, assessing and supporting carers in a personalised and outcome-focused way and on a consistent and uniform basis (p. 4).

The strategy draws attention to the need for support, but also the physical demands of caregiving: "With appropriate support, especially support delivered early to prevent crisis, caring need not have an adverse impact on carers" (p. 1):

The physical demands of caring can be immense, leading to exhaustion and having an impact on emotional wellbeing. This is especially so where both the carer and cared-for are elderly, or where the carer is caring for someone requiring a lot of moving and handling due to limited or no mobility (p. 73).

The importance of unpaid carers and the need for support for them is restated in other key documents (Scottish Government, 2007a, 2010c).

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It is not known how many unpaid carers support an individual who is a wheelchair user. It is, however, clear that the issue of the needs of carers with respect to such support are virtually unknown. It is of concern that the needs of carers who manage wheelchairs are not mentioned in any of the key Scottish policy documents referenced above. A word search of these publications found no references of any kind to wheelchairs in any of these strategies and reports. Nevertheless, the issue merits attention. Carers who regularly push wheelchairs usually support people with a high degree of physical dependency, often over many years (Office for Public Management, 2006) while they themselves are ageing. Though paid carers are protected by employment regulations on moving and handling, unpaid carers are not, and usually do not receive relevant training, either in moving and handling or in wheelchair management.

All NHS wheelchair and seating services in Scotland currently work to national eligibility criteria published by Rehabilitation Technology Information Service (2011). Of the types of wheelchair available, three require carer propulsion/control, i.e. attendant controlled manual wheelchairs (AC); indoor/outdoor powered wheelchairs with dual control for occupant & attendant (EPIOC dual); attendant controlled electrically powered outdoor wheelchairs (EPAC). In addition, users of occupant controlled manual wheelchairs (OC) may also on occasion need a carer's help with pushing the chair. All wheelchairs are issued subject to user criteria. Carer criteria are not laid down for manual (AC and OC) chairs, but are specified for both types of powered chair (EPIOC dual and EPAC). For EPAC chairs, the criteria specify exceptional circumstances making a manual chair impossible for a carer to push, i.e. that:

- the patient is over 18 stone weight (115 kg) and the weight difference between the attendant and the patient plus wheelchair is greater than six stone (38 kg);
- the patient's manual wheelchair would require a configuration which is inherently difficult to propel (e.g. extended wheelbase, forwards position of centre of gravity); and
- the patient's manual wheelchair inherently would be heavy to propel (e.g. heavy seating systems, heavy, medical equipment essential to life, etc.).

In acknowledgement of the problems inherent in the prescription and use of wheelchairs, the Scottish Executive published *Moving Forward*, an independent review of NHS wheelchair and seating services, following consultation with users and carers (Scottish Executive, 2006a). The report made 40 recommendations, including that "[...] assessment to ensure compatibility with carer requirements: The assessment will include review of the particular requirements of carers ensuring that any equipment provided is compatible with their requirements" (Recommendation 15). The rationale for this recommendation states:

The assessment will take into account any limitations or concerns that affect the carer (e.g. strength, risk of falls or injury, ability to assist with transfers) in supporting the user with the proposed equipment. In addition carers may face challenges due to their own health requirements, living environment or geographical location. Users have reported that they consider this to be an important part of the assessment (p. 35).

The subsequent *Wheelchair and Seating Services Modernisation: Action Plan* (Scottish Government, 2009) simply asks that wheelchair issues are included in existing carers' assessments and case management. The plan does not make any suggestions on communication and referral pathways between the NHS and social work services.

The location for the present study was the region of Fife in the east of Scotland. A proportion of those cared for by unpaid carers in Fife is among the 7,000 wheelchair users in the region. This represents around 2 per cent of the population – the highest in Scotland and in excess of 1.45 per cent, the national figure of carers. Some wheelchair users are substantially independent under normal circumstances; however, if tired or unwell, or if there are access or weather problems, they need help with their wheelchair. Others continually need support with all aspects of their daily lives involving mobility and postural management. Their carers, usually family members or sometimes friends, must undertake many daily moving and handling tasks, including wheelchair management. This involves: pushing the person in their wheelchair, both indoors and outdoors through a variety of spaces and over differing surfaces and gradients; transferring the person in/out of the wheelchair; and, for many, transferring the wheelchair and its occupant in and out of vehicles. Without adequate support, these carers must carry on caring, even when ill or injured. Members of the present project team reported that musculoskeletal problems were common, including back and shoulder injuries reported by those who push wheelchairs. However, there are no data available as to the number of carers who support wheelchair users, the demands placed on them, or the adequacy of the assessment of the carer's needs with respect to supporting a wheelchair user.

While occupational and engineering research has investigated best practice for wheelchair users in prescription and enhancing mobility (Abel and Frank, 1991; Smith *et al.*, 1995; Reid *et al.*, 2002; Frank *et al.*, 2010; Holloway *et al.*, 2010; May and Rugg, 2010), the role of unpaid carers has been neglected. The current research explores the role of wheelchair management in the lives of carers, identifying the importance of assessing carers' needs when a wheelchair is prescribed, and the impact of wheelchair type and design on carers' health, wellbeing and quality of life. The carers involved support wheelchair users who require assistance to manoeuvre, propel, manage and transport a wheelchair, either all or part of the time.

## 2. Method

### *Participants*

The 10 per cent sample was randomly selected from NHS Fife's database of 7,000 wheelchair users, identified to the researchers only by numbers allocated to each questionnaire. The sample is closely comparable and representative of the total Fife database with respect to the principal demographic variables. Two-hundred and twenty-two questionnaires were returned, 191 of which were valid cases for analysis. To reach carers using privately purchased wheelchairs, short articles were placed in local newspapers, resulting in a further four completed questionnaires. A total of 195 cases were used for analysis yielding a 28.4 per cent return. The questionnaire did not include the very small number of those with EPACs.

### *Survey instrument*

Following piloting, the carer questionnaire was made up of 28 questions divided into four sections relating to: the wheelchair user, the carer in the community; the environment; and any further comments. Copies of the questionnaire are available from the second author.

*Ethical considerations*

Formal ethical permission was not required to undertake the survey. However, since carers can be reluctant to report difficulties with their caring role and health, they were assured on anonymity with respect to their involvement and the information provided.

**3. Results**

*Characteristics of cared for wheelchair users*

The profile of the wheelchair users indicated that the average age was 57 years and that they typically had long-term conditions, e.g. profound disabilities (29 per cent) or a degenerative illness (25 per cent). 56 per cent were in the overweight to obese category of BMI, while 61 per cent were described as totally dependent.

27 per cent required major assistance and 12 per cent minor assistance. Type of wheelchair is shown in Figure 1. Manual wheelchairs were predominantly used (90 per cent), almost all, 94 per cent, were provided by the NHS (Figure 1).

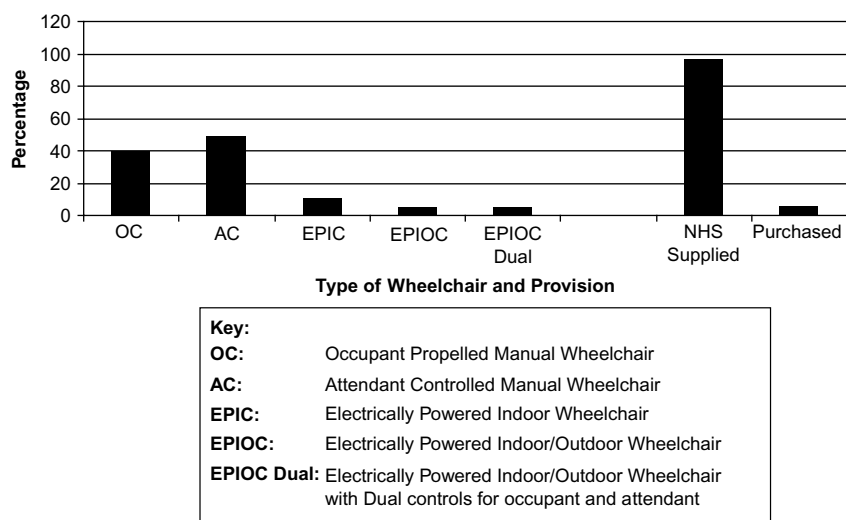
*Characteristics of carers*

The mean age of the carers was 54 years. 45 per cent were spouses or partners, 30 per cent sons or daughters, 16 per cent a parent of relative, 4 per cent friends while “others” made up 5 per cent. Significantly 65 per cent were overweight to obese as determined by their BMI. Three-quarters provided full-time care to a wheelchair user while over half were the only unpaid carer. 35 per cent pushed the chair more than four times per day.

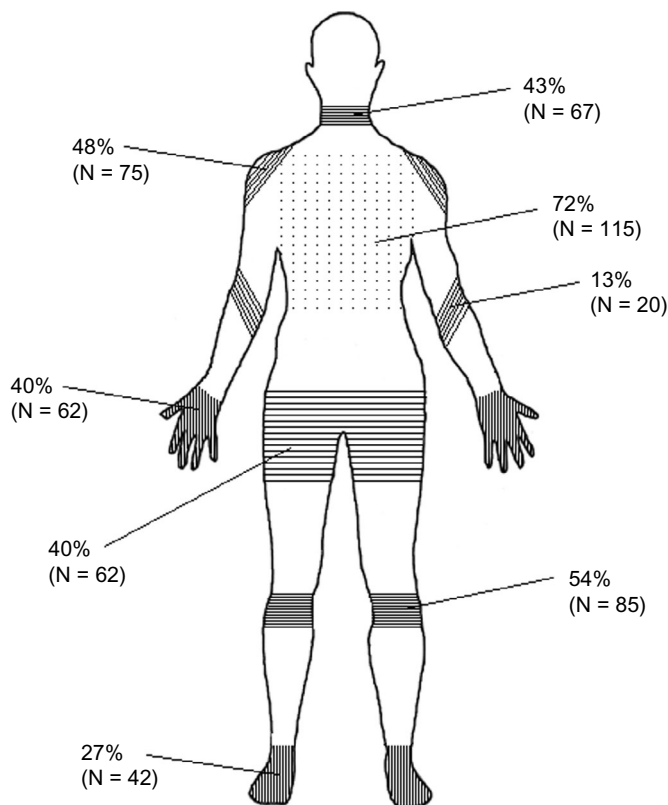
Overall, physical and other health problems were widely reported by carers, 86 and 62 per cent of carers, respectively. As may be shown in Figure 2, back problems predominated (72 per cent). Knee, shoulders and neck pain was also frequent, as well as pain in other joints.

42 per cent of carers had health problems, with breathing (19 per cent), heart (12 per cent) and/or balance (11 per cent).

Importantly, 81 per cent of carers in the survey had not received a carers’ assessment.



**Figure 1.**  
Percentage of users across  
types of wheelchair and  
provision



**Figure 2.**  
Percentage and frequency  
of reported  
musculoskeletal problems

#### *Type of wheelchair in relation to ages of user and of carer*

The data suggest a link between the type of wheelchair provided and the ages of user and carer. With EPIC and EPIOC dual (electrically-powered wheelchairs), most users were aged 20 years or under, 39 and 63 per cent, respectively, and most carers were under 60 years, 50 and 81 per cent, respectively. With OC and AC (manual wheelchairs), most users were 40+ years, 82 and 28 per cent, respectively. Most carers of OC and AC wheelchair users were also aged 40+ years, 25 and 41 per cent, respectively.

#### *Carer pain and other health issues and type of wheelchair*

There are differences in carer pain and health issues linked to type of wheelchair. As shown in Table I, carers pushing manual wheelchairs experience more pain and health issues than those managing electrically powered chairs. Shoulder pain for example is over four times as common for carers pushing manual wheelchairs as for those where the user has an EPIOC indoor/outdoor powered chair. Carers pushing manual wheelchairs are also much more likely to report heart, breathing or balance problems than those supporting powered wheelchair users.

Pain	<i>n</i>	OC <i>n</i> = 64	AC <i>n</i> = 74	EPIOC <i>n</i> = 19	EPIC <i>n</i> = 8	EPIOC D <i>n</i> = 8
Elbows	20	7	3	6	1	2
Shoulders	74	21	22	5	1	4
Ankles/feet	40	11	9	5	1	2
Hips/thighs	60	16	16	6	1	4
Knees	83	21	25	7	4	3
Neck	66	16	21	4	3	3
Back	113	29	39	8	3	4
Wrists/hands	61	15	19	6	1	2
<i>n</i>	154					
Heart	22	46	41	18	18	5
Balance	21	43	52	5	5	10
Breathing	35	31	57	9	6	3
<i>n</i>	59					

**Table I.**  
Percentage of pain  
reported by carers and  
type of wheelchair  
pushed

*Carers' physical problems compared with wheelchair user dependency*

Tables II and III show that carers of more dependent users as defined by extent of caring experience more frequent pain. For all types of pain, a higher percentage of full-time carers report pain in each of the eight areas of the body than do part-time carers. For most areas, this is in excess of three times higher percentage of reports by the former.

Pain in	<i>n</i>	Full-time carer ( <i>n</i> = 115)	Part-time carer ( <i>n</i> = 39)
Back	115	57	18
Knees	83	42	12
Shoulders	75	36	12
Neck	66	33	10
Hips/thighs	62	32	8
Wrists/hands	61	31	8
Ankles/feet	41	23	4
Elbows	20	11	2
<i>N</i>	154		

**Table II.**  
Percentage of pain  
reported in relation to  
amount of care

Pain	<i>n</i>	Totally dependent ( <i>n</i> = 93)	Needs major help ( <i>n</i> = 46)	Needs minor help ( <i>n</i> = 17)
Back	115	47	19	8
Knees	84	35	15	4
Shoulders	75	32	12	4
Neck	67	28	12	3
Hips/thighs	62	25	13	2
Wrists/hands	62	24	12	4
Ankles/feet	41	18	6	2
Elbows	20	10	3	1
<i>N</i>	156			

**Table III.**  
Percentage of pain and  
health conditions in  
relation to user  
dependency



*Carers' views on whether or not their needs were considered during wheelchair assessment*

62 per cent of carers reported that their needs had not been considered during wheelchair assessment. 76 per cent reported that their health needs had not been taken into account.

*Environmental conditions*

39 per cent of carers in the survey reported not having suitable home adaptations for wheelchair use; steps, tight corners and limited space being the most frequently cited problems. 62 per cent of carers said that their needs were not taken into account when the wheelchair was prescribed. As Table IV shows, steps, tight corners and limited space presented difficulties in over 60 per cent of these cases. Outside, many carers also had access difficulties, including on public transport and in shops.

*Carer training in wheelchair management*

77 per cent of carers reporting wheelchair management and/or pain difficulties reported they had not received wheelchair management training. For those who had not received wheelchair training, 36 per cent had experienced shoulder pain compared with 12 per cent who had experienced shoulder pain but had received wheelchair training. 55 per cent of carers who had not received training experienced back pain compared with 18 per cent who had received wheelchair training. Rates of wrist and/or elbow pain were 33 and 11 per cent, respectively, in untrained carers, compared with 7 and 2 per cent experienced by those who had received training.

**4. Discussion**

The study identifies an ageing population of unpaid carers, most of whom supported someone using a manual wheelchair. 83 per cent of carers surveyed reported having at least one problem; this included problems with the heart, balance and breathing, and bodily pain. A clear picture emerges of carers struggling physically to support wheelchair users. They may also be reluctant to report difficulties with their caring role and health. These results should, therefore, be treated conservatively.

81 per cent of carers in the study reported musculoskeletal pain in multiple sites. Back, neck, shoulder and knee pain were particularly common. This is consistent with recent research into musculoskeletal problems in primary caring (Jordan *et al.*, 2010). A striking link between wheelchair management and carer pain emerges: 72 per cent of carers in the sample had back pain, compared to 52 per cent of the Scottish population reporting such pain (Scottish Government, 2010b). The study clearly indicates that carers are more likely to experience pain if the wheelchair user is very dependent and needs frequent care. Of those who had difficulty managing the wheelchair, a majority

**Table IV.**  
Specific barriers noted by percentage of carers who reported environmental difficulties

Issue	No. of carers	Percentage
Not wheelchair friendly	72	39
Steps	51	69
Tight corners	47	64
Limited space	46	62
Steep ramps	5	7



had received no training, though those who had reported that they had benefitted. These findings strongly emphasise the importance of training for carers.

Wheelchair management problems could be made worse by unsuitable chair design, e.g. wheelchair handle height and weight. Problems with wheelchair provision, delivery and repairs were also raised. This is important because the unsuitability of a wheelchair to a user impacts on carers and their ability to manage the chair. Calculations were made based on Health and Safety Executive (1992) guidance concerning employees working in controlled conditions. These guidelines (1992) state that employees working in such conditions pushing wheelchairs that weigh over 30 kg for female carers and 55 kg for male carers increase their risk of physical injury when maintaining the chair's momentum on gradients of 1:12. Unpaid carers, however, are not protected by such policy or by legislation. It is important to note that these figures do not take into account other factors that affect the safety of pushing a weight (e.g. flooring, length of time pushing and carer health).

The point at which a person loses mobility to the extent that they require a wheelchair is a major transition for both user and carer, with obvious implications for their physical and emotional well-being, and the practicalities of their daily lives. Wheelchair referral and assessment are important opportunities for NHS staff to systematically identify carers with particularly demanding responsibilities, in line with the duty on NHS Boards to identify carers and their needs, as set out in the Scottish Executive's (2006b) *NHS Carer Information Strategies: Minimum Requirements and Guidance on Implementation*. All NHS wheelchair referrals in Scotland are currently made to WSS by either a GP or an allied health professional. A substantial majority of patients are not offered specialist assessment at a wheelchair clinic. For example, many older people and those with long-term conditions who have lost mobility are issued with a standard manual, attendant-controlled wheelchair without being seen at WSS. Many are dependent on spouses or other relatives of a similar age to push the chair. Systems for identification of carers are, therefore, needed which would be set in motion by GPs and allied health professionals making the referral, as well as by WSS themselves.

There is no doubt that WSS staff is committed to addressing carers' needs, working within the limited resources and staff time available. However, partnership structures with social work services and other agencies are not in place to support a holistic approach to users' and carers' needs and circumstances. As it stands, the NHS wheelchair system leaves excessive scope for carers to fall through the net.

Designing local generic carer assessments to cover all groups is problematic. 'Add-in' self-assessment pages on specific needs such as wheelchair management could capture the needs of carers, without making impractical additional demands on busy health professionals. Electronic wheelchair referral forms would include a prompt to the referring general practitioners and allied health professional to raise carer needs with the family, together with an attached pdf file of the carer self-assessment form to pass on to them. Similar arrangements should also apply to WSS clinical assessment processes. Self-assessment would give the carer control over information sharing and confidentiality. It could inform both clinical wheelchair assessment, and service planning with other relevant agencies such as community health, social and housing services. Carers should also receive 'signposting' information about relevant services. Materials for families such as information packs on wheelchair management could be also developed nationally.

The research makes a strong argument that carers of people who use wheelchairs should be offered holistic health checks, focusing on risk factors for cardiovascular disease and diabetes, offering appropriate interventions and services, and providing follow-up. Checks should also cover musculoskeletal problems and pain.

The carer criteria noted in the introduction also require comment. They appear to be based on considerations of the safety of third parties. They do not take into account the carer's own health and wellbeing, their age, physical size and strength (except, for EPAC chairs, where the disparity in weight is extreme). Nor do they consider the physical impact of pushing a manual chair on carer health, regardless of current levels of carer fitness.

In the present sample, a majority of the least fit and older carers supported manual wheelchair users. A link between the type of wheelchair and the pain that carers experienced was also demonstrated, with less frequent pain reported by carers helping powered wheelchair users. In other words, the effect of the current system appears to be that the least fit carers were less likely to receive equipment that could prevent a further deterioration in their health and wellbeing.

Safety considerations are obviously essential, but should apply to all concerned, i.e. user, carer and any third parties. If a carer's health problems are incompatible with safety, communication protocols should trigger an assessment of carer need. Current carer criteria have been set very high, effectively rationing resources and should be reviewed. Wheelchair design and provision must also be more responsive to the health needs of carers as well as users (Smith *et al.*, 1995).

There is clearly a case for attendant-controlled powered wheelchairs from many carers who would benefit. Those supporting users of powered wheelchairs are less likely to experience physical pain and health problems while the current criteria for prescribing electrically-powered chairs do not address carers' needs sufficiently. The findings on safe loads for pushing suggest that the current threshold for user weight of 18 stone (without the added weight of the wheelchair) is very significantly in excess of a safe load, even when pushed on a flat smooth surface. This threshold should, therefore, be reconsidered.

National Procurement figures indicate that over 50 per cent of electrically powered chairs and 10 per cent of manual chairs are privately purchased. NHS statistics also show that nearly 95 per cent of wheelchairs purchased by the NHS are manual. The literature on wheelchair prescription has already made a case for wider NHS provision of electrically powered chairs. One study has pointed to the risk of carer back pain due to manual wheelchair management (Abel and Frank, 1991) while Frank *et al.* (2010) show that carers experience a reduced burden and an increase in independence with use of electrically powered wheelchairs.

### **Conclusion**

Scotland's increasing number of unpaid carers represents an extraordinary human resource. Each in his or her way demonstrates on a personal level a model of what a caring society should be, especially those giving long hours of support, often around the clock. The *Carers' Strategy for Scotland* (Scottish Government, 2010a) outlines a picture of the key role that unpaid carers will play in Scotland's future, due to demographic and social changes:

- Scotland's 65+ population is projected to rise by 21 per cent between 2006 and 2016 and by 62 per cent by 2031; and
- for the 85+ age group, a 38 per cent rise is projected by 2016 and by 2031 the increase is a projected 144 per cent.

By 2031, there will be larger numbers of very old people and a proportionately smaller, younger working and tax-paying population (Scottish Government, 2006a). This implies serious consequences for the future of care in Scotland with an additional 25 per cent demand for health and social care services by 2031. With the ageing population, the number of carers is expected to grow to an estimated one million by 2037. Three out of five people in Scotland will become carers at some point in their lives. Some older carers may require more support in their own right. Society as a whole will become even more dependent on carers' vital contribution to health and social care delivery.

Carers assisting wheelchair users form a significant part of this increasing population. The research raises serious concerns about their health and wellbeing as well as about current arrangements for carer identification and assessment and communication between the NHS and local authorities. It suggests that a co-ordinated review of carers' wheelchair issues should take place, focusing in particular on: carer identification and assessment; health checks; wheelchair eligibility criteria as they affect carers; accessible information; and wheelchair management training. Further research should also be undertaken into the implications of carer's needs for wheelchair design and safe loads for pushing.

The argument for wider access to carer-propelled powered wheelchairs has also been set out. Research into the health economics of investment in powered wheelchair provision would be of great value, setting this expenditure against the costs of failure to support carers by providing this equipment. If carers are forced by damaged health to stop caring, the costs to statutory agencies would include very expensive services, needed by both the carer and the person cared for, such as home-based or residential care and preventative healthcare. Specific recommendations arising from the research are available in the original research report (Roberts *et al.*, 2011) which is available at: [www.pamis.org.uk/cms/files/wheels\\_turning\\_report\\_with\\_cover\\_final\\_28april11.pdf](http://www.pamis.org.uk/cms/files/wheels_turning_report_with_cover_final_28april11.pdf)

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