CARERS Scotland
the voice of carers

Sick, tired and caring

The impact of unpaid caring on health and long term conditions

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Summary

Data from the Census in 2001 found that carers are a third more likely to be in poor health than non carers.[1] The more recent Scottish Household Survey found that 12% of carers reported that they were in poor health. This increases to 18% for those caring for 20 hours or more each week. 12% of people termed in the Scottish Household Survey as "economically inactive"[2] providing care also consider themselves to be permanent sick or disabled.

Building on this evidence, this survey[3] by Carers Scotland reports on:

- the nature of the self reported levels of ill health amongst carers
- the prevalence of long term conditions
- the impact of general practice /primary health in supporting carers health and well being

Profile of carers in the survey

67% of respondents were female and 22% male[4] . Although sent to a randomised group of carers all of the respondents were 40 or over. The largest proportion of respondents were aged 50-59, reflecting the peak age for caring[5], with 49% of carers being retirement age or older.

- 10% aged 40-49
- 34% aged 50-59
- 28% aged 60-69
- 15% aged 70-79
- 6% aged 80 or over[6]

The majority of carers (66%) had been caring for at least 10 years, with one carer having cared for more than 45 years. 9% had cared for between 1 and 5 years and 13% for between 5 and 10 years.[7]

As well as caring for a significant period of time, the majority of respondents provided care for 50 hours or more each week (56%), with 6% caring for 20-34 hours and 6% caring for 35-49 hours. 7% provided up to 20 hours of care each week.[8]

"…Epileptic, asthmatic and have only sight in one eye. Back problems as have an abnormal spine (scoliosis) unable to walk for constant pain. Knee and hip problems. I do all lifting and carrying etc. So tired - Feel like running away."

Impact of caring on health and wellbeing

96% of respondents reported that caring had impacted negatively on their health and wellbeing. Only 4% said that it had not.

[1] Census 2001
[2] This term is commonly used but is appropriate and disliked by carers as they are providing unpaid work which contributes to the economy, saving £7.6 billion each year.
[3] 68 carers from across Scotland took part in this survey
[4] 11% did not provide their gender
[5] Census 2001
[6] 7% did not provide age details
[7] 12% did not provide details of the duration of their caring role
[8] 25% did not provide details of the level of their caring role

When asked in what way caring had impacted on their health and wellbeing:

- 70% reported back or shoulder pain.
- 86% reported that they suffered from stress, anxiety and depression
- 41% suffered from a range of illnesses including arthritis, high blood pressure, diabetes, chronic fatigue/fibromyalgia and IBS which were caused or exacerbated by their caring role.
- 34% experienced exhaustion whilst 10% experienced frustration, resentment and anger.
- More than half (54%) said that they felt isolated and could not take part in leisure or social activities or meet with friends and family.

"Back, leg, shoulders, feet and hand pain, high blood pressure, TIAs, arthritis, stress, sleeplessness, depression, anger. Little or no activities - L's needs have to come first."

Respondents were asked to rate their state of health.

- 27% rated their health as poor or very poor
- 40% rated their health as average
- 21% rated their health as good.
- Only 4% rated their health as excellent.

These carers were asked whether or not they had illnesses or disabilities. 57% responded that they did; *including amongst those who had rated their health as average or good*.

This level of long term illness or disability is more than twice the level of the general population[9] .

[9] Characteristics of Adults in Scotland with Long Term Health Conditions, Scottish Government 2007 found that 23.6% of adults in Scotland had a long term health condition or disability.

"I have depression, high blood pressure, swollen legs from varicose veins, asthma sufferer, stomach and bowel problems. Total exhaustion through being up attending to my husband anything from 2-5 times a night and no time to rest during the day."

Many of the sample had more than one and in some cases three or four long term conditions.

- 68% experienced a range of physical problems including carpal tunnel syndrome, white finger; pain in hips, legs, back and neck; and chronic pain.
- 37% suffered from arthritis, osteoarthritis or osteoporosis
- 34% high blood pressure or heart problems
- 13% had respiratory problems including asthma, COPD and sleep apnoea
- 11% had neurological problems including acquired brain injury, stroke, epilepsy and nerve damage
- 8% had sensory impairments including partial sight and hearing loss
- 45% had illness including diabetes, depression, underactive thyroid, hernia and fibromyalgia; 11% have or have had cancer.

Almost half the carers (42%) reported that their conditions had started after they began caring. Of those whose condition pre-dated their caring role, a quarter said that their condition had worsened since they took on their caring role.

"Exacerbation of existing carpel tunnel in both wrists (cleaning, changing beds, and ironing) plus backache and headaches. Long term exhaustion leads to low immune system (i.e. more colds).

Despair at lack of support/general help leads to chronic insomnia (also a case of getting over-tired) Frustration and continual stress has led to high blood pressure and weight gain - loneliness too. It's very difficult outwith any respite care that is available occasionally to have any leisure time. Friendships have to be long distance/end of telephone as socialising is nil. Work suffers as I can't commit to certain hours "

Duration, gender and hours cared did not seem to have significant impact on reported health. Males were slightly more likely to report poor health (93%) as opposed to females (91%) and those caring for 10 years or more were slightly less likely to be in poor health (91%) as opposed to 100% for those caring 1-5 years and 5-10 years.

Types of support that would promote health and wellbeing

We asked carers what would help their health and wellbeing. Unsurprisingly, better services and support were rated as very important. As reported in other surveys[10] of carers, the largest proportion (75%) of carers felt that the most effective support was a *regular* and appropriate break from caring.

"… a break away now and then would benefit me more than anything."

Many carers also stressed the importance of more services for the person they care for (40%) and better, more useful aids and equipment (31%)

"Better help for the person you care for as it will make the carer feel less stressed."

Many carers (22%) were also keen to utilise the benefits of new technology and telecare. However, only 53% of respondents were aware of telecare and only 19% were using or had access to telecare. The majority (92%) were using community alarms with only 8% using additional sensors including bed and epilepsy sensors.[11]

Income and finances continue to be a factor in affecting carers' health and wellbeing. A significant proportion of respondents (45%) indicated the difficulties they experienced due to low income. This included losing carers allowance on receiving their state pension, costs of services and support for the costs of travel to appointments.

"… help with travel costs as travel expenses take a large proportion of my meagre income."

As is well established, poverty and disadvantage are closely linked to poor health outcomes and, amongst carers, recent research[12] identified that many carers face a simple choice between heating and eating with more than 53% reporting cutting back on food and 60% on heating.

"… I lost my carer allowance when I received my state pension, although I am still in my caring role. My son is my work 24/7 – no holidays, no time off for sickness, no pension fund, no self worth."

[10] Care 21: the future of unpaid care in Scotland, Scottish Government 2005
Hearts and Minds, Carers Scotland 2006 and other reports

[11] The report "A weight off my mind", Carers Scotland, 2009 gives further consideration on the benefits and impact of telecare for carers.

[12] Carers in Crisis, Carers UK and Carers Scotland, 2008

Respondents were keen to have opportunities for their own personal and social development, to reduce isolation and to enjoy activities that benefited their own health and wellbeing. Put simply, to have a life of their own.

However, a lack of appropriate support and services, poverty amongst carers can often create a barrier to enjoying these day to day activities including opportunities to improve their own health and wellbeing.

Research[13] has evidenced that many carers have cut back on leisure activities and hobbies (81%) as well as holidays (88%), and seeing friends (80%).

"Company… It can be very lonely sometimes."

More than half of the carers in *this survey* felt that regular access to social or leisure activities would benefit them (57%). Moreover, 40% believed that carers should be entitled to a concessionary or free entry to council leisure activities.

"More opportunities to take part in leisure activities [would be] wonderful… Concessionary or free leisure at council facilities - but would have to be at flexible times where I could perhaps fit it in."

Education and lifelong learning is important to carers with almost a third (31%) asking for more opportunities and improved access.

Carers were also keen to have better support to enable them to remain in or return to employment.

40% believed that providing support in this way would improve their health and wellbeing.

"… I have had to give up work owing to my poor health and caring role. I want to escape the poverty trap.

Impact on general practice on carers' health and wellbeing

Almost all of the respondents (91%) said that their GP knew that they were a carer which indicates that initiatives[14] to improve identification of carers within practices have been beneficial.

However, despite this improved identification, 73% said that their GP had offered little or no help.

"…Has told me I am not tolerant enough that I lack 'patience' with my husband and mother."

A significant proportion of carers (37%) believed that GP practices needed to do more. This included simple changes such as making appointments more accessible and suitable for carers.

"If I've a personal health problem it is always a hassle to get an appointment - there's always such a delay before a doctor will see you."

The role of the GP and practices is integral to supporting carers' health and wellbeing. Almost half (46%) of carers wanted an annual health check.

[13] Carers in Crisis, Carers UK and Carers Scotland, 2008

[14] Such as NHS Carer Information Strategies, Scottish Direct Enhanced Services

"More help from GP or Practice - help with fitting in appointments. I feel this is stressful trying to fit in appointments for 3 people (3 different surgeries) and myself. Can only book appointment 2 days in advance and more often than not there's none available…"

Only 27% had received help from their GP but were very positive about this support which had included organising a flu jab or counselling, arranging suitable appointments and referring onto other agencies.

"The doctor has been fantastic and he takes care of me and daughter."

Discussion

This survey confirms a key finding from previous research[15], namely, many carers suffer ill-health as a result of caring.

It provides further and more detailed insights into the nature of the negative impact of caring and highlights that for many carers the health problems they face are significant, long term and often multiple**.**

The survey also highlights the paradoxical role of general practice, namely the potentially pivotal role in providing support, identifying illness and in preventing ill health; with the reality that this does not happen in many instances. It also highlights the need for better more coordinated services and support from primary health care.

The implications of not receiving appropriate supports have far reaching consequences not just for carers' health but for the care of those cared for and importantly for the health care system.

There are many costs associated with poor health in carers. The first is direct costs in treating the carer's own health problems. The second is the potential costs that would result if the carer is less able to care because of their ill-health. Given that carers' support is worth an estimated £7.6 billion a year, these costs could be considerable. Finally, there are other indirect costs associated with ill-health – if carers cannot work whilst caring or when their caring role ends because of this ill health, there will be lost contributions to the tax and revenue system as well as associated costs on the benefits system.

Some health costs are avoidable. Providing information, at the right time, so that carers can access available financial and practical support, to manage caring better, reduces poverty, disadvantage and ill-health. Similarly, an improvement in the level and quality of support, or flexibility can help to improve carers' health and prevent ill health. Whilst providing support in the current economic climate is difficult, the potential costs to the economy are greater if carers' health breaks down.

Prevention, earlier intervention and anticipatory care will have greater impact in reducing negative effects.

[15] Hearts and Minds: the health effects of caring, Carers Scotland 2006

Recommendations

1. Carers' health and wellbeing is disadvantaged simply by virtue of taking on a caring role. **Preventing ill-health amongst carers should be an integral and targeted element of public health planning**, involving a range of agencies planning to reduce health inequalities amongst disadvantaged groups.

2. **All carers should have access to an annual health check.** Early intervention is critical to ensure that carers do not develop or exacerbate ill health whilst caring. The planned approach in the Scottish Government's Carers Strategy to utilise the Keep Well and Well North programmes will aim to reach eligible carers aged 45-64 in the 15% most deprived areas in Scotland is welcome[16].

   However, given the mean age of the respondents to this survey (40 and over), it is clear that by this stage it may already be too late to prevent carers from developing long term conditions.

   Earlier identification and intervention is needed and an annual health check can help identify those carers at risk and thereby prevent future ill health.

3. To prevent ill health such as back injury caused by the physical tasks of caring, **all carers should be offered access to practical training** to support them in their caring role at the outset of the role.

4. Carers should be encouraged and supported to access leisure activities to develop improved health. **To support this, Local authorities should be encouraged to offer or, where already available, continue to provide concessionary rates to carers for leisure activities such as swimming.** This could initially be targeted at carers in receipt of or with an underlying entitlement to carers' allowance.

5. **The role of GPs should be reassessed**. General practitioners have a key role to play as, for many carers, a GP will be their main or only contact with statutory services. However, it could be argued that too much reliance is placed on the ability of GPs to fully support carers given the considerable pressures of other priorities placed upon them. Therefore, consideration should be given to the appointment of a named practitioner within each practice/health centre to overview the support systems for carers.

   The Scottish Government will work with the Royal College of General Practitioners Scotland on its plans to provide guidance to GP practices in Scotland on carer and young carer identification[17] and both will work with national carers' organisations to better identify and support carers, including promoting good health. These initiatives are to be commended and we hope they will be successful.

[16] Action Point 12.5, "Caring Together: The Carers Strategy for Scotland 2010-2015", Scottish Government and CoSLA, 2010

[17] Action Point 8.4, "Caring Together: The Carers Strategy for Scotland 2010-2015", Scottish Government and CoSLA, 2010

However, all GPs should not only be encouraged to identify carers and refer them to suitable sources of support but also to ensure that appointments for carers are available at times that are suitable.

The role of GPs is also critical in ensuring that carers are supported to manage multiple long term conditions and to prevent carers developing these conditions in the first place.

6. **Carers with significant caring responsibilities should be entitled to a guaranteed minimum number of hours of respite care/break from caring each week.** This should be offered to carers who are caring in excess of 35 hours each week and/or where the nature of the care provided is such that, if withdrawn, the cared for person would require either residential or nursing/hospital care. Ideally this should be organised in such a way that meets their particular circumstances and available from the relevant health authority.

   Breaks for carers to prevent ill health and enable carers to access social and leisure activities should be seen as a critical element of any support package.

7. **Carers should have access to information at the right time and in the right place**. Systems such as the new NHS Inform Carer Zone are welcomed but, much more emphasis should be placed on ensuring that carers have information at the very beginning of their caring role.

   Information should be made readily available through acute hospitals, primary care, GPs and community services and a requirement should be placed on NHS Boards to ensure that information for carers is provided to all patients and their families before discharge from hospital and on diagnosis of long term conditions which are likely to merit the need for assisted care.

8. Carers Assessment is a key element in ensuring that resources can be maximised in supporting carers effectively. **Carers should have timely access, ideally within 6 weeks, to a Carers Assessment and this should be reviewed after 6 months and thereafter on an annual basis**.

   The assessment should include a range of issues including access to income maximization and what support is needed to ensure that carers can remain in employment. Employment is often overlooked in assessments but as it is a key route out of poverty for carers, current employment status and employment aspirations should be a key consideration within assessments.

9. Moreover, **the role of new technologies particularly telehealthcare should be explored further as a mechanism to reduce poor health**. Evidence from research[18] identifies key health and wellbeing benefits including more peace of mind, less stress and worry, a better nights sleep and the ability to have a break from caring Telehealthcare needs to become an integral part of community care and carer assessments and consideration of telecare as an option should be integrated into assessment protocols.

[18] A weight off my mind: Exploring the impact and potential benefits of telecare for unpaid carers in Scotland", Carers UK and University of Leeds, 2009

However, charges for telecare should be transparent and equitable and should be kept affordable to ensure that carers are not disadvantaged by costs.

Awareness of telehealthcare and its benefits to carers must be raised amongst health and social care workers and GPs, social workers and hospital staff should be targeted to ensure that help gets to carers at the appropriate time.

10. **All strategic policies and plans** particularly in relation to community care and the future health care needs of older people **should be carer proofed** ensuring that the burden of care does not shift to unpaid carers. Policy to move more care to the community must not place more burden on carers. Carers' role in making these happen is critical and policymakers must consider the needs of carers to support their own health and wellbeing and to care safely as a key element of their planning.

Conclusion

The role of carers is rarely "chosen". It is often thrust upon individuals as a consequence of a sudden illness, a disability or accident of a family member, partner or friend or the birth of a disabled child. Therefore, carers require information to be provided at an early stage about the illness and disability of the person they care for, the structures and systems of the NHS and social services and, significantly, on meeting their own needs. Professionals in health and social care *must* acknowledge this requirement and respond appropriately.

Information and effective support is critical. Poorly coordinated planning and a lack of information and support leads to stress, low self esteem and frustration and thus onto ill health for carers. This ill health is often ignored as carers do not have the time or back up to look after their own needs. This cannot be good for the carer and risks the breakdown of care with the subsequent need for intervention by health and social care. This will, inevitably, be more costly both financially and, most importantly, in human terms for the carer and the person they care for.

For many carers, caring makes them sick and tired… but, it does not need to be this way. With the right support, resources and information, caring can be a positive and rewarding experience, an ordinary feature of ordinary life.

What carers in the survey said

A number of carers in the survey made specific comments about their caring experience. Carers' voices are at the heart of all we do and their observations are included in this section.

About their health and wellbeing

"Tired out, stressed, irritability, some depression too. Boredom as loss of my own dependence. Back pain and hips/knee (r). Sleep disorder - up and awake at 4:30/5am etc. Continuously thinking of all I need to do to keep ahead of tasks for husband (as depressed and physically disabled) and mother - Alzheimer's. Lack of activities - tied to house. No outside leisure. No holiday in 8 years. No friends - isolated and lonely."

"Exacerbation of existing carpel tunnel in both wrists (cleaning, changing beds, ironing) plus backache and headaches. Long term exhaustion leads to low immune system (i.e. more colds). Despair at lack of support/general help leads to chronic insomnia (also a case of getting over-tired) Frustration and continual stress has led to high blood pressure and weight gain - loneliness too. It's very difficult outwith any respite care that is available occasionally to have any leisure time. Friendships have to be long distance/end of telephone as socialising is nil. Work suffers as I cannot commit to certain hours "

"Back, leg, shoulders, feet and hand pain, high blood pressure, TIAs, arthritis, stress, sleeplessness, depression, anger. Little or no activities - Linda's needs have to come first."

"I suffer from back pain, collapsed disc base of spine, also arthritis in left knee. I believe this is due to years of caring for elderly parents and also now my husband who is disabled through osteoarthritis. Also having to do all jobs such as gardening, DIY around the house. Stress, I have been on anti-depressants for many years due, I believe, to my caring duties. I have been married 41 years and in that time I have only had 2 years that I have not been caring for one or many people. Don't have any leisure time. I care for my husband 24/7, also my daughter part time who has similar problems to her father and also a dear friend part time who has no family of his own. He is also very disabled with spine problems. The truth is my life is theirs and I look after my 3 year old grand daughter 5 (half days) per week. The Government wants mothers now to work but this means that grannies who are often carers like me are left to look after the grand children. Yes we love them to bits but boy it's exhausting on top of everything else."

"I have osteo-arthritis, type 2 diabetes, sleep apnoea and fibromyalgia. All of these impact on my ability to care and on my own health."

"Epileptic, asthmatic and have only sight in one eye. Back problems as have an abnormal spine (scoliosis) unable to walk for constant pain. Myself - knee and hip problems. I do all lifting and carrying etc. So tired - Feel like running away."

"I have depression, high blood pressure, swollen legs from varicose veins, asthma sufferer, stomach and bowel problems. Total exhaustion through being up attending to my husband anything from 2-5 times a night and no time to rest during the day."

"Atrial fibrillation. Mastectomy in 1991…Osteoporosis"

"Although at present I am off work due to stress related illness, looking after a young person (20 year old son) has finally caught up with me and I have been signed off with fatigue and ability to cope."

About support that would promote their own health and wellbeing

"More than anything a break away now and then would benefit me more than anything."

"Respite where I can be confident that the person(s) I am caring for will be safe and properly cared for and related to (social depravation) also where the bed is comfortable and the food is edible!!) Respite is very hard to obtain - granny-sitting voluntary care so that I can go shopping, leave the house. An information helpline that is really effective."

"Practical help i.e. housework."

"More ongoing therapy to aid cared for's rehabilitation."

"Better help for the person you care for as it will make the carer feel less stressed."

"More opportunities to take part in leisure activities [would be] wonderful but where would I find time? …Concessionary or free leisure at council facilities – this would be wonderful but would have to be at flexible times where I could perhaps fit it in."

"Company… It can be very lonely sometimes."

About finances

"Financial - I lost my carer allowance when I received my state pension, although I am still in my caring role. My son is my work 24/7 - no holidays, no time off for sickness, no pension fund, no self worth."

"…help with travel costs as travel expenses take a large proportion of my meagre income."

"I just want to be left alone instead of battling with social security for money to live on as I have had to give up work owing to my poor health and caring role. I want to escape the poverty trap.

About the support they receive from their general practice

"Hasn't. Has told me I am not tolerant enough that I lack 'patience' with my husband and mother."

"If I've a personal health problem it is always a hassle to get an appointment - there's always such a delay before a doctor will see you."

"The doctor has been fantastic and he takes care of me and daughter."

"More help from GP or Practice - Help with fitting in appointments. I feel this is stressful trying to fit in appointments for 3 people (3 different surgeries) and myself. Can only book appointment 2 days in advance and more often than not there's none available…"

"More time to speak with GP. 2 minute appointments are okay if you have something small to see too, but carers have lots to deal with and talk about. I constantly feel under pressure to speak quickly to fit all problems into 2 minutes. Ok you can ask for double appointment but that's even harder to get. As for appointment for myself I tend not to bother, there's just no time and the system makes it too difficult. Even double appointments are often not enough time anyway for all we carers have to discuss. I feel there should be a member of staff trained to help and listen to carers. Have say carers meetings at different times so all carers have the chance to attend and have their say/problems discussed."

Who is Carers Scotland?

Carers give so much to society yet as a consequence of caring they experience ill health, poverty and discrimination. Carers Scotland is the Scottish nation office of Carers UK and is an an organisation of carers fighting to end this injustice. We will not stop until people recognise the true value of carers' contribution to society and carers get the practical, financial and emotional support they need. Carers Scotland is here to improve carers' lives.

- **We fight for equality for carers.** We want carers to have the same right as everyone else to an ordinary life – a fair level of income, access to support to protect their health and wellbeing and access to the world of work, leisure and education.

- **We seek to empower carers.** We want carers to be actively involved in the design, development and delivery of services. We want carers to be recognised and involved as key partners in the provision of health and social care services.

Carers Scotland achieves this by:

- campaigning for the changes that make a real difference for carers
- providing information and advice to carers about their rights and how to get support
- mobilising carers and supporters to influence decision-makers
- gathering hard evidence about what needs to change
- transforming the understanding of caring so that carers are valued
- providing training for professionals and carers

Training service

Carers Scotland runs training days for professionals working with carers. The courses range from carers benefits to advocacy and from carers' assessments to carers' rights. Visit www.carerscotland.org or call the Carers Scotland training service on 0141 445 3070.

Carers UK Adviceline

Carers UK provides high quality advice and information to carers and the professionals who support carers. This is available through our websites, booklets, factsheets and our advice line which is staffed by experts and has years of experience of dealing with the problems carers face. We provide information and advice on:

- benefits and tax credits
- carers employment rights
- carers' assessments
- the services available for carers
- how to complain effectively and challenge decisions.

Call 0808 808 7777 (Open Wednesday and Thursday 10am-12pm and 2pm-4pm. Answerphone at other times).

Join us!

Together we can make a difference

Join Carers Scotland and Carers UK today and help bring your voice to campaigning for changes to make a difference to carers' lives.

Standard membership is free to carers and former carers. We welcome any individual who supports our aims and also offer affiliate membership for organisations in the voluntary, statutory and private sector.

To find out more visit www.carerscotland.org or contact our membership hotline on 020 7378 4999.

Donate and support our work with carers!

Please help support our work in providing advice and information to carers from across Scotland by making a donation. You can donate online at www.carerscotland.org or by contacting Carers Scotland at the address below.

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