

Under pressure: supporting unpaid carers in Wales

Introduction

Unpaid carers make a vital contribution to society – the economic value to Wales of their work has been estimated at £7.72 billion per year. Their role can be very rewarding, deepening and strengthening relationships through providing relatives, friends and loved ones with the often vital support they need. However, the demands of the role are also considerable.

This briefing looks at the work of unpaid carers in Wales, the pressures they face, and some of the ways that they cope. It puts forward recommendations for action to ensure carers are better supported.

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A role that matters

Carers have been defined as people of any age who provide unpaid care and support to family or friends who could not manage without this help.² Unpaid carers work alongside professionals, other volunteers, care homes, special schools, and community groups, often caring for people in their own homes.³ There are an estimated 370,000 unpaid carers in Wales,4 and this number is likely to increase with an ageing population and increasing prevalence of chronic illnesses. The Welsh Government acknowledges that at least 70% of the care for vulnerable people in Wales is provided by unpaid family, friends and neighbours, and that 100,000 people in Wales regularly provide over 50 hours of unpaid care per week, i.e. far more than a standard working week.5

"The reasons people might need help can vary. Maybe they were born with a disability or had an accident that left them disabled. Or they have an illness or disease. Their problems may be physical or mental. They might need help because they are getting older and frail. But what doesn't vary is that they need help, and if you look after someone - for whatever reason - caring is part of life."

Carers UK, 20126



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A demanding role

Caring roles are often very demanding and time consuming and, as a result, carers often come under considerable pressure and stress, frequently to the detriment of their own health. A recent survey of nearly 3,400 carers across the UK found that 83% stated that caring had had a negative impact on their physical health, and 87% said it had adversely affected their mental health. Carers are often forced to ignore or suppress such health worries, however, with over a third of respondents (39%) stating that they had put off medical treatment as a result of their caring responsibilities.

The findings of this survey at a UK level correspond closely with research undertaken in Wales by Alcohol Concern in collaboration with the former Princess Royal Trust for Carers (now part of Carers Trust) and local carers' centres. This research in 2011 included a survey of local carers' centre managers, a focus group of carers in north Wales, and an anonymous survey of over 800 carers in 5 counties in Wales.

"As years of caring progress, the carer's health deteriorates. The years pass and you look back on your own missed years of being unable to have a break."

Carer responding to an Alcohol Concern survey, 2011⁹

The responses to the survey of carers highlighted the intense demands on many of them. 95% of respondents identified fatigue and exhaustion as one of the main problems

faced by carers.¹⁰ This is understandable given that 73% said that they were providing more than 50 hours of care per week, and 46% had been caring for more than 10 years. The survey also found that:

- 84% felt isolated
- 87% mentioned financial pressures long hours of caring mean that carers are often unable to undertake paid employment
- 91% lacked time for themselves
- 80% felt that their caring role was not recognised
- 92% said they did not get enough support.

"I soon realised my wife and I were alone. Until one has experienced years of caring for someone, no other will ever understand."

Carer responding to an Alcohol Concern survey, 2011¹¹

Other pressures carers described included:

- Lack of personal life and loss of personal identity
- Lack of time for people other than the cared for person
- Changes in their relationship as the caree becomes more dependent, e.g. a marriage between two equal partners can become a very different relationship when one partner becomes the other's carer
- Difficulty with statutory services, often contrasting with a very positive attitude towards local voluntary sector services.

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How carers cope

The survey also looked at the ways carers cope with the demands on their time and energy:

- 69% of respondents relied on friends and family for support, but 27% were not able to
- 40% used respite services to help them cope, but 26% did not see this as an option, and another 20% did not appear to be aware of respite opportunities
- 93% felt that they "just had to get on with it".

"[l] invent reasons to go out for a short while, if only to walk around the block."

"I always feel free when I go out and do a bit of weeding or planting."

Carers responding to an Alcohol Concern survey, 2011¹²

The responses of many carers showed that they were drawing on their own resources to help themselves cope, and looking for opportunities to relax that could be fitted around their caring role:

- Hobbies and distractions that could be done at home (such as reading and gardening) were mentioned, as was simply getting out the house for a short while, .e.g. to walk the dog
- The internet provided a link to life outside their caring role for some, and gave opportunities to connect online with people in a similar situation to themselves
- Religious faith was important for many people, both in itself and as an opportunity to socialise at their place of worship

 Some said they sought escape through comfort eating, drinking alcohol, or prescription medications.

Alcohol as a coping mechanism

"When there's a crisis, that's when you need a drink. Carers have a lot of crises."

Comment from carer in an Alcohol Concern focus group, 2011¹³

Overall, 20% of survey respondents said they had used alcohol to cope with the pressures of caring. Alcohol was also mentioned in response to open questions about ways of coping:

- "[Alcohol] is the only piece of solace available to me."
- "I do have a drink most nights I have 2 maybe 3 glasses of wine. I don't go out in the evening and although I have very good close friends I am on my own with my daughter. It is a really lonely life and unless you have a responsibility like my life you really can't understand what it is like."
- "I drink frequently. If more help was available then people would not rely on alcohol."¹⁴

"The use of alcohol is to a point socially acceptable, readily available and something a carer can do in isolation without having to leave the home...perhaps one pleasure that they can take part in without requiring respite."

Survey of carers' centre managers, 2011¹⁵



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The Mental Health Foundation has described alcohol as a "favourite coping mechanism" in the UK,¹⁶ and the reasons for this are not hard to discern:

- Alcohol is very easily available, and its use is commonplace and generally acceptable
 87% of adults in Wales say they drink alcohol¹⁷
- Its use as means to relax and relieve stress, as well as a means to socialise and celebrate, is a strong social norm.

Use of alcohol in this way is not necessarily problematic. However, it needs to be remembered that whilst often taken to enhance mood, alcohol in fact slows our mental and physical processes and can worsen physical and mental health. It is also potentially very addictive, and prolonged excessive use can lead to problems of psychological and physical dependence. When alcohol is regularly used as a means to cope with ongoing stress, the dangers can be particularly acute.

Added to this are the difficulties carers may face in getting more information or support if they are experiencing problems with alcohol. Alcohol Concern's survey²⁰ found that:

- 82% thought carers would be too busy with their caring role to seek help
- 79% said not knowing where to go could be a barrier
- Perhaps most significantly, 83% thought stigma or embarrassment were factors. A similar percentage (84%) cited the fear that someone would be seen as a "bad carer" if they were known to have a drink problem.
 Stigma around alcohol problems is common

and not confined to carers, of course,²¹ but does appear to be intensified by the perception that a carer with an alcohol problem is, by definition, one that is failing in their caring role.

Supporting carers

On the positive side, there was strong interest from survey respondents in information and support options around alcohol that were flexible, accessible and confidential – three principles that are clearly relevant to any kind of support services for carers, and not specific to alcohol-related problems. Indeed, the responses to this section of the survey highlighted a number of points that are more broadly applicable.

There was some interest in printed or online general information about alcohol (57% favoured this) and in finding out more about alcohol as part of a general healthy living session for carers (70%). However, the strongest support was expressed for one-to-one confidential support and for forming support groups with other carers:

- 83% thought that one-to-one confidential support would be "quite helpful" or "very helpful", including 62% who thought it would be "very helpful"
- 77% thought at a support group of other carers would be "quite helpful" or "very helpful", including 49% who thought it would be "very helpful".

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Survey questions about the most suitable venue or setting for providing information and support highlighted two conflicting issues which are common to all carers support services:

- The fact that some carers are unable to leave their homes due to caring responsibilities: "Being a carer 24/7, home would be the only option if I drank."
- The need or desire of some carers to leave the home environment – which is, in fact, their work environment – in order to:
 - Be able to concentrate on their own issues without being drawn into caring tasks
 - Have some privacy from their caree
 - Simply to be in a neutral space one carers' centre manager recommended using a venue "out in the community, especially somewhere with nice scenery...
 It provides a break from the home that may be causing the stress...[and] enables carers to have a change of scenery and think a bit more clearly."²³

The responses from carers reflected this dichotomy:

- 71% favoured providing support in carers' own homes
- 79% favoured support in a local carers' centre or support group.

This concurs with the conclusions of a recent report by the Care Council for Wales which also noted carers' own homes and day centres as alternative venue options for providing support for carers,²⁴ and it seems clear that a flexible approach covering both these options is needed when it comes to support around alcohol (and many other issues). As one carers' centre manager said: "We know that carers appreciate having options for getting information and support, so they can chose the service that best suits their needs."²⁵

Summary and recommendations

Unpaid carers play a vital role in supporting vulnerable people in our society, yet research shows that many feel isolated and lack recognition, and that their caring role often adversely affects their health and well-being, as well as their finances. Our research indicates that carers in Wales face substantial and long-term pressures as a result of their caring roles, and are seeking out various ways to cope with these pressures. The all-consuming nature of the caring role often means that carers feel unable to seek help with the problems they face, either because their attention is focussed on the caree, or because they simply do not have the time or the energy.

Given the demands caring places on their time, a package of flexible support is needed that carers can access at times and places suitable for them; confidentially, when necessary. Whilst many excellent services exist at a national and local level, it is clear that many carers are still not getting the support they need. To address this situation, Carers Trust and Alcohol Concern recommend:



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Recommendation 1

Carers provide vital support for vulnerable people in Wales, and through their unpaid work bring massive savings for public services. Funding for the social care services carers depend on needs to be safeguarded, so that carers can access good quality and reliable support. The Welsh Government and local government need to work together to deliver sustainable funding for social care, to meet unmet need and growing demand.

Recommendation 2

Carers need regular breaks from caring. 91% of carers told us they lacked time for themselves, and 92% said they lacked support. With a growing number of carers in Wales, and 73% in our survey caring for more than 50 hours per week, it is essential that funding for support and respite services is maintained or increased.

Recommendation 3

General Practitioners (GPs) and other primary care professionals have a key role to play in identifying and registering carers, monitoring their health and signposting them to advice, information and support. Primary care staff need to ensure they are fully aware of the support options available for carers. They can also help carers by identifying and recognising their caring role, and being flexible with appointment times, ensuring that they are made at the times most convenient for carers.

Recommendation 4

Carers need a safe and secure environment to be able to discuss their coping mechanisms, including use of alcohol, and to be supported in looking at alternatives if they are worried there may be a problem. This is likely best achieved by equipping local carers' services staff with the skills they need to provide targeted support that is relevant and accessible, and that acknowledges the particular needs and circumstances of carers, be that on a one-to-one basis, via peer group sessions, or through more formal training sessions. Relevant written and/or online information will be needed to back up this work.

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Alcohol Concern

Alcohol Concern is the national charity on alcohol misuse campaigning for effective alcohol policy and improved services for people whose lives are affected by alcohol-related problems. We are working at a national level to influence alcohol policy and champion best practice locally. We support professionals and organisations by providing expertise, information and guidance. We are a challenging voice to the drinks industry and promote public awareness of alcohol issues.

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Tel: 029 2022 6746

Email: acwales@alcoholconcern.org.uk Website: www.alcoholconcern.org.uk

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