Carers Strategy and COVID recovery planning for unpaid carers

Health and healthcare

The case for action

1. The impact of caring on health

It has long been clear that caring has often significant impacts on the health and wellbeing of unpaid carers and a range of evidence is available.

- Carers Week research from 2018\(^1\) found that 6 out of 10 people (61%) said their physical health had worsened because of caring, while 7 out of 10 (72%) said they have experienced mental ill health.
- With the impact of the pandemic, the most recent State of Caring 2021, found 72% of carers said that their mental health has deteriorated, and further 72% that their physical health has got worse because of caring in the pandemic. Currently 30% of carers in Scotland described their physical health as bad or very bad. 35% of carers rated their mental health as bad or very bad.
- VOCAL recent survey results\(^2\) from carers in Edinburgh and Midlothian also highlight a significant decline* in carers’ health and wellbeing since their last survey. 66% felt that ‘being a carer has affected my physical health’ and 79% that ‘being a carer has affected my mental health’.
- Carers are more likely to be in poor health\(^3\), with 6 in 10 (60%) of carers surveyed stating they had a long-term condition, disability or illness compared to half (50%) of those who weren’t caring. Of these carers, almost two-thirds (64%) report that this condition reduces their ability to carry out day-to-day activities.
- The conditions that carers were most likely to have were arthritis or ongoing back or joint problems (21%) and high blood pressure (17%), both of which may be affected by the stress and physical demands of caring. Indeed, carers were far more likely to have either of these conditions than those who aren’t caring, who reported these conditions at 16% and 15% respectively.\(^4\)
- As hours of caring increase, negative impacts on health increase, for example, in 2014 32% indicated that their health was negatively impacted by their caring role and this rose to 41% in those providing 50+ hours of care, with 41% saying that they had a physical long term condition or illness (double the rate of non-carers).\(^5\)
- The Health and Care Experience Survey in Scotland has reducing numbers of carers who say that caring has NOT has a negative experience on their health 44% in 2013/14 v 38% in 2019/20\(^6\).
- Older and retired carers were most likely to have a long-term condition (76% and 79%). However, younger carers under 25 and carers who are not in paid work were markedly more likely to state that these conditions affect their day-to-day activities (78% and 80%), suggesting that even though these groups are less likely to have a long-term condition, the effects of these conditions have a far greater impact on their lives\(^7\).

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\(^1\) Carers Week (2018) Supporting Carers to be Healthy and Connected
\(^3\) Carers’ health and experiences of primary care Data from the 2021 GP Patient Survey, Carers UK
\(^4\) ibid
\(^5\) Health and Care Experience Survey in Scotland
\(^7\) ibid
Isolation and Loneliness

- Looking at wider indicators of wellbeing, 38% of carers in State of Caring 2021\(^8\) reported that they are often or always lonely, otherwise known as being ‘chronically lonely’.
- Carers also rated their overall satisfaction with life at an average of 4 out of 10 and their level of anxiety at 6 out of 10. Carers Week 2019 research found that carers are 7 times more likely to say they are always or often lonely compared with the general population.\(^9\)
- The impact of isolation on health is wide-reaching, including increased risks of death, cognitive decline, dementia, coronary heart disease and stroke.\(^10\)

Carers with protected characteristics

Minority ethnic carers

- There is some evidence that BAME carers have slightly higher levels of poor health than other carers (0.6% higher in England than White British carers). This evidence also indicated that the Indian community (7%) are the biggest BAME group of carers who are suffering from poor health. The Black Caribbean (6%) and White Other communities (6.4%) of carers also showing high levels of poor health.
- Carers with a mixed ethnic background were much more likely to report feeling isolated compared to other ethnic groups.\(^11\)
- Almost three-quarters (74%) of carers from ‘Other ethnic backgrounds’ reported an impact on their day-today activities compared to 69% of carers from a Mixed ethnic background. 68% of Asian carers, 63% of White carers and 59% of Black carers.\(^12\)
- Research conducted by Netto found that 31% of respondents were in poor or very poor health. The peak age for caring of this group was younger than those within the general population, 21-40 years (as opposed to 50-64), more likely to be female (76% v 59%) and nearly half (48%) were unable to speak English.\(^13\)
- Research conducted by Carers UK\(^14\) also identifies that BAME carers are more likely to be caring for a sick or disabled child and in particular, an adult son or daughter aged between 20 – 24 years, which reflects long term and enduring caring responsibilities and resultant impact on health and wellbeing. The research also highlighted that BAME carers are significantly more likely to be providing between 20 – 49 hours of care per week than their White counterparts. Earlier research noted the association between more hours caring and poor health. People caring for longer also experienced poorer health.
- Asian carers were also more likely to have been shielding, with almost half (46%) reporting that they had been shielding compared to between 37-39% of carers from all other ethnic groups. Asian carers and those from mixed ethnicities were also most likely to have avoided making a GP appointment, with 61% of carers from both groups stating they had avoided the GP compared to 40% of those who weren’t caring and just over half (51%) of all carers.
- Services that support carers and improve wellbeing are often not accessible to people from BAME communities nor do they meet cultural needs. For example, a study undertaken with ethnic carers of older people in Edinburgh and the Lothians found that almost 70% of carers did not use any of the services provided by social work or by voluntary organisations (Netto, 1996).

Lesbian Gay and Bisexual Carers

- State of Caring 2021 also found that LGB carers are slightly more likely to feel lonely (93%) than heterosexual carers
- LGB carers are also more likely to say that not being able to get out of the house has made them feel lonely and socially isolated (63%), compared to 52% of heterosexual carers.
- LGB carers are also more likely to be experiencing a long-term mental health condition. Over a third (36%) of lesbian, gay and bisexual carers had a mental health condition compared to 13% of heterosexual carers, making them almost three times as likely to be experiencing a long-term mental health

\(^8\) State of Caring, Carers UK, 2021  
\(^9\) Carers Week (2019) Getting carers connected  
\(^10\) Campaign to End Loneliness: The Facts on Loneliness  
\(^11\) ibid  
\(^12\) ibid  
\(^14\) Half a Million Voices; Improving support for BAME carers, Carers UK, 2012
condition. This aligns with existing research that suggests lesbian, gay and bisexual people are more likely to have poor mental health than their heterosexual counterparts.  

- 7 in 10 (70%) lesbian, gay and bisexual carers report a long-term health condition or disability compared to 60% of heterosexual carers. Three-quarters (75%) of lesbian, gay and bisexual carers reporting a long-term condition stated that it affected their day-to-day life compared to 62% of heterosexual carers.

2. Accessibility of, and lack of support from, health services

This impact of caring in health is exacerbated by carers being unable to find time for medical check-ups or treatment

- Two in five carers said that they were forced to put off treatment because of their caring responsibilities – unable to trust or find suitable and affordable replacement care.
- VOCAL’s recent survey found that over 50% also reported that their caring role has resulted in missed or postponed appointments or a delay in treatment for their own health.

As a result of putting off medical treatment because of caring

- It made the problem worse for 49 per cent of carers.
- It extended the time for which carers are affected by the problem for 53 per cent of carers.
- It caused an additional illness for 22 per cent of carers.
- It stopped or made it harder for 26 per cent of carers to undertake their caring responsibilities.

GP’s have a critical role to play but often do not offer services and support to accommodate carers

Often GPs know about carers but do not offer additional support or accommodations

- Fewer than 1 in 10 (9%) of those whose GPs know they are a carer said that their GP had talked to them about general information, advice and support for being a carer or where they could go to get this. This was lowest for those providing care for a disabled child (5%) and highest for carers over 75 years old (18%).
- Only 5% of carers said their GP had spoken to them about information on getting exercise and eating healthily. And only 1% of carers said their GP had spoken to them about information on making social connections. Only 2% of carers reported that their GP had spoken to them about how to get regular breaks from caring.
- Young adult carers and those caring for a disabled child were the most likely to say that their GP had raised none of the issues we suggested, with half of carers in these groups reporting this.
- Although most of the carers who were caring for at least 50 hours a week in a Carers UK survey had a GP who knew of their caring responsibilities (84%), of these carers, most (71%) said that their GP didn’t do anything differently to accommodate them. Very few had a GP who gave regular carers health checks or did home or telephone appointments.
- A Carers Week survey from 2016 found that over half (65%) of carers had not been informed about how to access practical support by their GP and that almost half (45%) of carers’ GP practices did not offer an annual health check.
- Where GP didn’t support carers through signposting or health checks, over half of carers reported that they left a health problem go untreated (54%) and that their mental health got worse (63%).

3. COVID19

As well as exacerbating impacts on health outlined in section 1, the pandemic has also reduced access to carers to GP appointments, crucial in supporting their health and wellbeing.

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15 Carers’ health and experiences of primary care Data from the 2021 GP Patient Survey, Carers UK  
16 ibid  
17 Carers Week (2012) In Sickness and In Health, published by Carers UK  
19 Carers Week (2012) In Sickness and In Health, published by Carers UK  
20 Carers Week (2018) Supporting Carers to be Healthy and Connected  
21 ibid  
22 Carers’ health and experiences of primary care Data from the 2021 GP Patient Survey, Carers UK
Almost 4 in 10 (38%) carers had been shielding had not made appointments compared to 23% of people who weren't caring. 

Carers from all backgrounds were also more likely to have avoided the GP, with over half (51%) saying they had avoided making an appointment compared to 40% of those who weren’t caring.

Wider delays in healthcare, restricted access to support services and physical activity have also had an impact on the condition of the person being cared for with over 7 in 10 (71%) of carers saying the needs of the person they care for have increased, just 1% have said the condition of the person they care for has got better.

This increase in needs of the person who is being cared for has had a direct impact on the health and wellbeing of carers. They report increased levels of stress and anxiety (91%), deteriorating mental health (77%) and deteriorating physical health (67%). Over two thirds of carers said that their ability to undertake physical activity had got worse and around half (48%) said their confidence in their ability to care had decreased.

4. Future impact of health and wellbeing on ability to care

A carer’s health and well-being can have a significant impact upon their ability to provide support for the person they care for. There are implications for the ability of unpaid carers to provide care in the future.

- Almost half of carers (43%) said that they expected that they will be able to provide less or no care in the future because of poor current or future physical health. Over a third (35%) said the same of mental health.23
- Older carers, especially those over 75 years old, were most likely to say they expected to be able to provide less or no care in the future because of poor physical health (54% of over 65s and 59% of over 75s).24
- When all groups were considered, carers in Scotland were more likely than carers in other nations to expect to be able to provide less or no care in the future because of poor physical health (48% compared to a UK average of 43%).

5. Actions for a Carers Strategy and COVID recovery plan

Actions for the Scottish Government

Phase 1 – COVID Recovery

- Ensure that carers continue to be prioritised for any future COVID boosters and annual flu vaccination. Vaccination planning should ensure that carers and those they care for can easily access such vaccination within their own locality.
- Provide updated guidance to on hospital visiting and carers to NHS Boards to:
  - ensure that carers are treated as essential visitors within hospitals including accompanying the person they care for to emergency department, in ambulances (both emergency and scheduled care) to outpatient appointments and in visiting in-patients.
  - instruct them that an unpaid carer can accompany the person they care for and should be actively supported to continue to provide support. This should be beyond those caring for someone with a learning disability or dementia.
  - reinforce carers rights in hospital discharge. It is vital that health services understand the criticality of the role of unpaid carers in support, advocating for their loved one and in planning for discharge. This planning for discharge should begin from the point of admission, as per guidance set out in the Carers (Scotland) Act 2016.
  - develop contingency plans for periods where COVID rates are higher and normal visiting may be restricted.

23 Carers Week (2018) Supporting Carers to be Healthy and Connected
24 Ibid
• Provide better and more regular information for carers of people who are at high and higher risk to help understand changes to guidance and various stages in the pandemic. Carers need good information to help them make informed choices about risk and activities. This includes activity to increase public awareness and understanding.
• Continue to prioritise unpaid carers for PCR testing alongside other health and social care workers.
• Continue to provide free PPE and lateral flow testing for unpaid carers.
• Consider evidence for expanding access to anti-viral medication to a wider group of people more at risk (outwith those at highest risk) and to unpaid carers.

Phase 2 (Carers Strategy)

• Develop and expand social prescribing for unpaid carers in all areas. For example, free access to leisure, health and wellbeing activities to unpaid carers, alongside the introduction of a national unpaid carer discount card, with similar benefits to the Young Scot National Entitlement Card
• Develop strategy and guidance to enable local areas to offer health checks for unpaid carers to identify health concerns or pre-conditions, such as high blood pressure
• Develop strategy and guidance to enable local areas to offer flexible G.P appointments for unpaid carers of all ages, including longer appointment times at times which are suitable for unpaid carers and provide home visits where necessary

Actions for NHS and HSCPs

Following national strategic direction and actions, all NHS Boards and HSCPs should set out clear and measurable plans to outline how they will deliver priorities to improve carers health, as outlined above. In addition, to reflect the significant impact of caring on health and as part of remobilisation and recovery plans, they should:

Phase 1 (Covid Recovery)

• Provide detail of how they will ensure that carers will be able to easily access or spot purchase replacement care to enable them to access healthcare appointments and treatments – both in primary and secondary care. This should include dental services. Plans should include how each partnership will provide support to enable a carer to have sufficient recovery time after treatment.

Phase 2 (Carers Strategy)

• Provide detail on how they intend to ensure that carers will be contacted where they have not taken up routine screening during the pandemic.
• Provide detail on how they will roll out and/or expand social prescribing in their area
• Provide detail on how they will delivery health checks and flexible healthcare appointments for carers

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