

# The need for a new National Carers Strategy



This is not an official publication of the House of Commons or the House of Lords. It has not been approved by either House or its committees. All-Party Parliamentary Groups are informal groups of Members of both Houses with a common interest in particular issues. The views expressed in this report are those of the group.

## This report was researched and funded by Carers UK: May 2024

## About the APPG on Carers

The All-Party Parliamentary Group (APPG) on Carers is Chaired by Dame Caroline Dinenage MP, and Co-Chaired by Baroness Jill Pitkeathley.

The aim of the group is to ensure that the millions of people in the UK who provide unpaid care for ill, older or disabled relatives and friends get the recognition and support they need.

The APPG brings together parliamentarians from across the political spectrum, alongside policy and practice experts, to raise awareness, to share knowledge, and improve understanding of the needs of unpaid carers in parliament.

The APPG works on a cross-party basis and provides a forum for parliamentarians and expert stakeholders to discuss what can be done across the NHS, social care, employment policy, and the social security system to improve the lives of carers. Officers of the APPG on Carers for 2024/25 include the following:

- Chair: Dame Caroline Dinenage MP
- Co-Chair: Baroness Jill Pitkeathley OBE
- John McDonnell MP
- Wendy Chamberlain MP

John Perryman, Policy and Public Affairs Manager, Carers UK provides the secretariat for the All-Party Parliamentary Group (APPG) on Carers.



## Introduction

The All-Party Parliamentary Group (APPG) on Carers is calling for the development of a new and ambitious National Carers Strategy, to provide a step change in the support that unpaid carers receive from UK Government and other key stakeholders.

The need for a new cross-Government approach to supporting unpaid carers is something that unpaid carers, national and local charities, and other organisations that represent them, have long been calling for.

The APPG on Carers' view is that the development of a new National Carers Strategy would enable the UK Government to better coordinate its support for unpaid carers across various Departments, publicly demonstrate its support for unpaid carers, and clearly communicate this to the public.

It would also set a clear direction of travel and look at the interaction between different policies and shared Government ambitions across different Departments regarding support for unpaid carers – ensuring that their needs are understood and being responded to at highest level of Government. These priorities include:

- Supporting carers to stay in / return to work
- Improving carers' health and wellbeing
- Supporting carers, improving population health
- Preventing poverty
- Combatting loneliness and social isolation
- Improving equality of opportunity and preventing discrimination.

Our call is for a new National Carers Strategy that is led by the Prime Minister, with clear buy-in and responsibilities for Secretaries of State for all Government Departments that have responsibility for policy relating to the provision of unpaid care. It also needs clear roles and responsibilities for other important stakeholders, such as NHS England, Association of Directors of Adult Social Services (ADASS), the Local Government Association (LGA), and to work in tandem with organisations who represent carers. Vitally, any such strategy should be developed and co-designed with current and former carers.

Such an ambition is commensurate with the need for any future strategy to have a bold and ambitious vision for how Government can work with other partners to ensure that those providing unpaid care get the support, recognition and value they need and deserve.

The findings of the public engagement exercise we recently conducted demonstrates that carers and organisations who represent them overwhelming support the call we are making. We want to sincerely thank the 5,032 individuals who took the time to engage with us. The views they shared with us have been vital in helping shape our call for the development of a new Strategy.

Since the end of the Carers Action Plan 2018-2020 in 2020, there has not been a dedicated cross-Government approach to supporting unpaid carers, and it has been 16 years since the last Carers Strategy was published by UK Government in 2008.

The development of a new National Carers Strategy should be a priority for the next Government. It would help millions of carers to continue caring for their family and friends while protecting their health, work, and wellbeing.

## Unpaid caring in context

Across the UK, 5.7 million people support and help to look after family members, friends or neighbours who are affected by long-term illness, disability, or older age, through the unpaid care they provide.

Census 2021 found that, since 2011, the number of hours of unpaid care being provided has increased significantly, with 1.5m people in England and Wales now caring for over 50 hours every week.

The economic value of the unpaid care people provide each year is a staggering £162 billion – similar to spending on the NHS. Per carer, that is an average of £28,421.00 a year.

The unpaid care people provide daily is a lifeline for millions of people, and carers play a vital role in supporting the UK's health and social care systems, offering essential support that complements the formal care provided by professionals.

Despite their huge contribution, far too many carers do not feel recognised or supported, and too often caring comes with significant challenges that have a severe and lasting impact on carers' own lives.

These challenges include:

- *Financial strain:* Many unpaid carers face financial difficulties due to the need to reduce working hours or leave employment altogether to provide care. Although some financial support is available, like Carer's Allowance, it is often not enough to offset the loss of income, and additional costs, people face due to their caring responsibilities.
- *Health and wellbeing:* The physical and emotional toll of caring responsibilities can be significant, with many carers experiencing stress, burnout, and health problems of their own.
- Access to support: Finding and accessing appropriate support can be extremely challenging and many carers report having to fight to get the support they need. This includes respite care, which is meant to enable carers to take a break from their caring responsibilities, and difficulties accessing information and advice or navigating health and social care services.
- **Recognition and visibility:** Unpaid carers often feel that their role is undervalued by society and that their needs and contributions are not adequately recognised by policymakers.

of respondents agreed that a new cross-Government National Carers Strategy should be developed by UK Government

### Previous Cross-Governmental work

The first national carers strategy, 'Caring about carers', was published by the UK Government in 1999.

This was followed in 2008 by, 'Carers at the heart of 21st-century families and communities'. This set out a vision that by 2018, carers would be universally recognised and valued as being fundamental to strong families and stable communities.

The current UK Government then developed the 'Carers Action Plan 2018-2020: Supporting carers today' in 2018, a two-year programme of activity in support of unpaid carers.

## The position of the APPG on Carers developing a new National Carers Strategy

In recognition of the significant and broad set of challenges that carers are currently facing, and the vital role they play in supporting millions of people and our health and social care systems, the APPG on Carers believes it is vital that there is a step-change in the way a future Government supports unpaid carers going forwards.

As a result, we are collectively calling for the development of a new and ambitious National Carers Strategy, to act as a catalyst for transforming the lives of millions of carers.

The APPG on Carers considers that any National Carers Strategy that is developed by a future UK Government should be:

- Broad and ambitious in its focus, covering the following areas: income and finances, employment, health and care, wellbeing and inclusion, learning and education, housing, young carers and equalities.
- Also focussed on key cross-cutting enablers such as: carer identification, recognition, the potential of technology, combating discrimination, health inequalities and data.
- Led by the Prime Minister, as previous National Carers Strategies were, to provide leadership and drive from the very heart of Government.
- Sponsored by a wide range of Secretaries of State / UK Government Departments, incorporating all with responsibility for policy relating to unpaid carers – including: HM Treasury, Department for

Health and Social Care, Department for Work and Pensions, Department for Business and Trade, Ministry of Defence, Department for Education, Cabinet Office, Department for Levelling Up, Housing and Communities, Department for Transport.

- Provided with significant ring-fenced funding for delivery by UK Government.
- Co-designed with unpaid carers and organisations who represent them.
- Ambitious in its aims for delivery, by UK Government and other relevant stakeholders, over a ten-year time frame.
- Operate on a UK-wide basis referring to and supporting specific carers in different nations, but recognising the role of the devolved Governments in those nations and their own carers strategies.
- Take into consideration and learn from good practice that exists internationally (and in other UK nations) in support of unpaid carers.

**99%** 

of respondents agreed that any future National Carers Strategy should be co-designed with unpaid carers and organisations that advocate on their behalf

# Findings from public engagement exercise

To ensure that our call reflected the wants and needs of unpaid carers themselves, we recently launched a survey asking current and former carers, as well as organisations who support and represent them, for their views on how any future National Carers Strategy should be developed, and what it should aim to achieve.

We are delighted that between 8 February 2024 and 7 March 2024, we received 5,032 responses to our survey. We want to thank each and every individual who took the time to share their views with us.

Of those who responded, 84% were current or former carers. 16% were organisations who represent unpaid carers or the people they care for.

There was overwhelming support for our call. 95% of respondents 'strongly agreed' (81%) or 'agreed' (14%) that a new cross-Government National Carers Strategy should be developed by the UK Government.

When asked which themes any future National Carers Strategy should focus on, respondents prioritised the following:

•	Carers' health and	l wellbeing:	93%
---	--------------------	--------------	-----

- Carers' incomes and finances: 90%
- Access to social care: 73%
- Identification and recognition: 72%
- Rights and equalities: 67%
- Supporting carers in employment: 66%
- Young and young adult carers: 61%
- Housing: 50%
- Learning and education: 47%

Nearly three quarters (74%) of respondents agreed that any future National Carers Strategy should be led by the Prime Minister at the heart of the Government. "Any National Carers Strategy should be owned by the Prime Minister, as this would demonstrate that unpaid carers are the political priority they deserve to be. Vital to the success of any strategy is to ensure clear milestones and clear responsibility for delivery. Prime Ministerial, or senior Ministerial, ownership of the strategy, together with a cross-government oversight board, would help drive delivery and ensure accountability for the success of the strategy."

When asked which Government Departments should be involved in the delivery of any future National Carers Strategy, respondents prioritised the following:

Department of Health and Social Care:	99%
Department for Work and Pensions:	86%
<ul> <li>Department for Levelling Up, Housing and Communities:</li> </ul>	60%
Department for Education:	50%
Cabinet Office:	27%
• Department for Business and Trade:	27%
Ministry of Defence:	9%

"Unpaid carers are everyone's responsibility and will be employees in every department. Strategy should be coordinated by the Cabinet Office. Department of Transport should be included."

"Also needs to include the Department for Local Government. Department for Culture, Media & Sport. Department for Transport. HM Treasury. Home Office. Ministry of Justice. Equality and Human Rights Commission. Committee on Fuel Poverty."



of respondents agreed that any future National Carers Strategy should be led by the Prime Minister at the heart of the Government

of respondents agreed that any future National Carers Strategy should be supported by dedicated and ring-fenced Government investment to deliver any agreed outcomes for unpaid carers

Almost all (99%) respondents agreed that any future National Carers Strategy should be co-designed with unpaid carers and organisations that advocate on their behalf.

"Definitely with National Carers organisations but with clear input from locally based carer support organisations. The lived experience of carers needs to be central to any future work in this area."

"A National Carers Strategy must be co-designed with those with lived experience of those who care for people living with dementia and clinical experience of supporting carers of people living with dementia. This ensures that the National Carers Strategy aligns with dementia carers' needs and considers health and social care systems as they exist on the ground."

"There are some principles which we feel should be reflected in any co-design/coproduction - Carers should be paid for their time (eg in case they need to obtain replacement care to take part); There should be enough lead-in time and support for carers wanting to be involved; carer involvement must be meaningful; There should be a diverse range of carers involved."

"Co-production is vital, any future Strategy must be produced in partnership with unpaid carers and those who advocate for them."

When asked over what timeframe any future National Carers Strategy should be delivered, 82% of respondents said 2 years, 14% said 5 years and 4% said 5-10 years. This is indicative of the widely held view that carers urgently need more support

from the Government as a matter of priority As a result, we would urge whichever party forms the next Government to announce plans to develop a National Carers Strategy, and hold any necessary consultation, following the General Election.

"All of the above - the strategy should consider short, medium and long term outcomes for carers. Some changes required are of the utmost importance and urgency; for example, tackling rising levels of poverty and financial hardship experienced by carers. Others may require longer term reforms."

"There should be prioritisation within a longer term strategy - so milestones along the way to help practically, all contributing toward the longterm agreed approach... realistically, some of the interventions will take time, and cognisant of the wider economic and public service issues that will, realistically, take 10+ years to redress."

"Support for unpaid carers is dire at the moment, we need help for people struggling now, but we also need mid to long term plans that can be implemented to make lasting change."

Likewise, almost all (98%) of respondents agreed that any future National Carers Strategy should be supported by dedicated and ring-fenced Government investment to deliver any agreed outcomes for unpaid carers. The Carers Strategy that was launched by UK Government in 2008 was supported by £255 million of funding to achieve the outcomes contained within it. We would like to see a similar level of ambition and commitment from any future Government when developing a new Strategy.

# Testimony from unpaid carers

We asked unpaid carers what difference a new National Carers Strategy would make to their lives. Below is a selection of the responses provided.



"Acknowledgement and support. The lives and health of carers is substantially detrimentally impacted by their caring roles. Help, information, advice and support (including financial) needs to be provided just to make things a little easier."

"Greater profile and focus, joined up thinking and delivery greater efficiency, effectiveness and value for money."

"It is very easy to forget about unpaid carers despite the enormous contribution they make - a National Strategy will ensure they stay on the Government agenda and targeted support can be developed. With an ageing population, more people will end up having caring responsibilities and if we don't support them appropriately it will only place more pressure on an already creaking and underfunded social care system."

"Would give credence to the value of unpaid carers and guide local authorities in their approach to commissioning, strategy, planning and delivery services."

"It would provide the appropriate pathways with commitment from cross-Government to improving and supporting unpaid carers in the short, medium and long term. "It would give specific guidelines and target to be met and find gaps that need filling."

"Unpaid carers would have more certainty as to what help they can expect and hopefully there would be more help available."

"A new Strategy will show carers that Govt is serious about demonstrating their recognition of the value of carers, the help we give the social services and hospitals and the necessity of supporting us so we can continue caring for our loved ones."

"You would know your rights as a carer, unlike at present where you have to find out for yourself, or with help from charities."

"Knowledge that we exist and, perhaps, hope for the future that things will improve."

"It would give much needed hope and hopefully a solid legal framework."

"Direction, support and funding secured to empower carers, recognise the value they bring and allow them to continue to do this valuable role, while also supporting their own personal and professional development flexibly around their caring role."

# ANNEX: Results from APPG on Carers survey

## 1) To what extent do you agree that a new cross-Government National Carers Strategy should be developed by UK Government?

Strongly agree:	81%
• Agree:	14%
Neither agree nor disagree:	4%
• Disagree:	1%
Strongly disagree:	1%

2) What are the key themes that should be included in any future cross-Government National Carers Strategy? Please tick all that apply.

Carers' health and wellbeing:	93%
Carers' incomes and finances:	90%
Access to social care:	73%
Identification and recognition:	72%
Rights and equalities:	67%
Supporting carers in employment:	66%
Young and young adult carers:	61%
Housing:	50%
Learning and education:	47%

 In your opinion, which of the following outcomes should be achieved for unpaid carers through the delivery of a future cross-Government National Carers Strategy? Please tick all that apply.

	<ul> <li>No carers are forced into poverty or financial hardship as a result of their caring responsibilities:</li> </ul>	89%
	<ul> <li>All carers will be supported to stay mentally and physically well and treated with dignity:</li> </ul>	87%
	<ul> <li>Carers will be able to have a life of their own alongside their caring role:</li> </ul>	85%
	<ul> <li>Unpaid carers will be recognised as fundamentally important to family and community life:</li> </ul>	83%
	<ul> <li>Carers are treated by the NHS and social care services as expert partners in care:</li> </ul>	82%
	<ul> <li>People will have access to the integrated and personalised services they need to support them in their caring role:</li> </ul>	81%
	<ul> <li>People will be supported to quickly identify themselves as unpaid carers, so they can get the advice, information and support they need:</li> </ul>	79%
	• Carers will receive the support and flexibility they need to juggle paid employment and unpaid caring responsibilities:	75%
)	Do you agree that any future cross-Government National Carers Strategy should be led by the Prime Minister at the heart of Govern	ıment?

• Yes:	74%
• No:	26%

4)

5) Which of the following Government Departments do you think should be involved in the delivery of a future National Carers Strategy? Please tick all that apply.

•	Department of Health and Social Care:	99%
•	Department for Work and Pensions:	86%
•	Department for Levelling Up, Housing and Communities:	60%
•	Department for Education:	50%
•	Cabinet Office:	27%
•	Department for Business and Trade:	27%
•	Ministry of Defence:	9%

6) Should any future cross-Government National Carers Strategy be co-designed with unpaid carers and organisations who advocate on their behalf?

• Yes:	99%
• No:	1%

### 7) The APPG on Carers is calling for a new cross-Government National Carers Strategy to be published as soon as possible. Over what timeframe should it's outcomes be delivered?

• 2 years (short):	82%
• 5 years (medium):	14%
• 5-10 years (longer term):	4%

8) Should a future cross-Government National Carers Strategy be supported by dedicated and ring-fenced Government investment to deliver any agreed outcomes for unpaid carers?

•	Yes:	98%
•	No:	2%



The aim of the All-Party Parliamentary Group (APPG) on Carers is to ensure that the millions of people in the UK who provide unpaid care for ill, older or disabled family or friends, get the recognition and support they need.

The APPG brings together Parliamentarians from across the political spectrum, alongside policy and practice experts, to raise awareness, to share knowledge, and improve understanding of the needs of unpaid carers in parliament.

The APPG works on a cross-party basis and provides a forum for Parliamentarians and expert stakeholders to discuss what can be done across the NHS, social care, employment policy, and the social security system to improve the lives of carers.

Carers UK provides the Secretariat for the APPG on Carers.



Carers UK 20 Great Dover Street, London, SE1 4LX T 020 7378 4999 | W carersuk.org | E policy@carersuk.org

Carers UK is a charity registered in England and Wales (246329) and in Scotland (SC039307) and a company limited by guarantee registered in England and Wales (864097). Registered office 20 Great Dover Street, London SE1 4LX.