# **National Carers Strategy**

**Executive Summary** 



# **Table of Contents**

Ministerial Foreword		
Intr	tion5 ind gender8	
	Demographic pressures	
	Intensive caring and deprivation	8
	Impacts of caring	8
1.	Living with COVID-19	9
2.	Valuing, Recognising and Supporting Carers	12
3.	Health and Social Care Support	15
4.	Social and Financial Inclusion	19
5.	Young Carers	22
6.	Monitoring	25
7.	Carer Quotes	26

# **Ministerial Foreword**



Unpaid carers make a vital contribution to ensuring that people throughout Scotland get the care they need.

The COVID-19 pandemic created significant difficulties and hardships for many carers. When support services closed or reduced capacity as part of the first lockdown in March 2020, carers stepped into the gap to support vulnerable friends and family members. For many people, this was never planned, but was utterly essential. The number of people providing care increased and many existing carers took on more intensive caring roles, while also losing the opportunity to take breaks from caring.

To add to this, Scotland is now facing the most severe economic upheaval in a generation with the current cost crisis, which is putting livelihoods, and lives, at risk. It is a humanitarian emergency, and as with the pandemic, carers are being affected disproportionately.

Many carers are standing up to draw attention to the challenges they are facing. We know from their eloquent and passionate testimonies that many of the effects of the pandemic are still being felt even while the burden of the cost crisis affects almost every aspect of life. The stories carers tell are varied and unique to their own situation, but they share many similarities. Too often they involve a struggle to get the right support, with carers themselves often having to navigate complex services that do not always seem to work together.

We know from listening to carers that they must take on these challenges while working, attending education and trying to lead their own lives. We know that sometimes their own aspirations are sidelined because they do not get the support they need. Most importantly, they must do all this while continuing to care for their loved ones. If there is one constant in all of the experiences carers share, it is their commitment to provide the best possible care, regardless of the obstacles they face. When carers talk about their lives, their focus is always on the person for whom they are caring.

Carers should not have to fight to ensure their loved ones get the support they need, they should not be required to put their own ambitions on hold and they should not have to campaign to demand basic services.

The pressures of the past two years have left many carers at breaking point. Many are now in acute need of support to alleviate their caring roles, enable them to have

breaks, support their own mental health and reduce isolation. More than ever, the contribution made by unpaid carers has to be recognised and steps taken to address the problems caused by the pandemic as well as the long-term, systemic issues that continue to affect unpaid carers.

It is with the lived experience of carers in mind that this strategy has been developed, and its implementation will be shaped by those who best understand the experience of being a carer.

For individual carers, the practicalities of our health and social care, education, housing, transport, social security and employment systems shape the intensity and experience of caring and their ability to balance caring with satisfying lives beyond caring.

Now is the time to set out a fresh vision for how we enable people to provide care for loved ones in a meaningful and sustainable way while still being able to work, attend education and have full lives away from caring. This strategy sets out a comprehensive range of actions to address five different aspects of unpaid carer support. It includes existing initiatives as well as new proposals, but the key is that we take a strategic approach to supporting carers, ensuring that their experience as carers is reflected in all of the services they use.

We want Scotland to be a place where all carers are recognised and valued for the contribution they make, where they are enabled to provide the right support for the people they care for while living full, rounded lives. No-one should need to put their aspirations and ambitions on hold because they are providing care to a loved one.

There are several key principles that must be central to our approach. We must make sure that providing care does not mean that someone needs to give up their job or reduce their hours, that it does not plunge them into financial hardship or social exclusion. All carers must be seen as equal partners in care, and involved in decisions relating to their caring role. We must ensure that the importance of unpaid care is recognised and that its value is acknowledged and respected, by the public sector, employers and by society. As part of this strategy, we will work with local carer centres and young carer services who play an integral role in helping unpaid carers access help and support, including raising awareness of carers' rights, helping people to recognise themselves as carers and to destignatise the term.

Unpaid carers are now, and will remain, fundamental to building strong families and partnerships and resilient and cohesive communities. We have a shared responsibility to support carers, to raise the profile and value of care and to work in partnership with everyone who has a responsibility to carers to ensure that carers receive the support they rightly deserve.

**Kevin Stewart MSP** 

Minister for Mental Wellbeing and Social Care

# Introduction

Unpaid care is vital to how social care is provided in Scotland, and the value of the dedication and expertise of carers cannot be overstated. This strategy recognises the diverse experiences of carers and sets out a range of actions to ensure they are supported fully in a joined up and cohesive way. It brings together existing initiatives and new approaches, and proposes new and better ways to support carers. It seeks to reflect both the diversity of careers' experiences and their lives beyond caring to avoid pigeonholing people as carers and nothing else.

For many people, caring is a positive experience. Those with the least intensive caring roles can experience better than average mental health and wellbeing. For many carers, the time spent with the person they are caring for can be a positive and rewarding experience, if supported appropriately.

Every caring situation is unique. Carers' individual needs and the impact of caring depend on all sorts of factors such as their age, health and ethnicity, and their support networks of family and friends. For example, minority ethnic carers face the same challenges as all carers, but also face additional barriers, for instance cultural barriers, stereotypes and language which can increase the chances of poorer health, poverty and social exclusion. The level and type of care provided is also a major factor. There are very different physical and emotional pressures from supporting someone with addiction, a mental illness, a physical disability or learning disability, or a progressive condition or terminal illness.

People in more intensive and stressful caring roles can often experience negative impacts on their health and wellbeing. Without the right kind of support and recognition, unpaid carers can face difficult challenges. The approach set out in this strategy seeks to ensure that unpaid carers can provide the best possible care, supported by a system that recognises and values their contribution, allowing them to lead a full life in addition to their caring role.

Without proper support and the ability to lead a full life beyond caring, a carer's health and wellbeing suffers. This has an impact on the cared-for person often resulting in greater need for health and care support, particularly for older people, such as admission to a care home or hospital or delays to hospital discharge.<sup>1</sup> Where the caring role leads to a carer leaving employment, this will affect their financial situation, their employer and the wider economy.

People who provide care to loved ones must be supported to do so in the most effective way and in a way that allows them to lead a balanced and varied life. The Carers (Scotland) Act 2016 aims to ensure that carers have choice and control, and can access preventative support to keep caring situations manageable. It puts in place a system of carers' rights designed to listen to carers, improve consistency of

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<sup>&</sup>lt;sup>1</sup> The Scottish Government (2015). Scotland's Carers report.

support and prevent problems – helping sustain caring relationships and protect carers' health and wellbeing.

Despite this, we know that unpaid carers can have too many burdens placed on them. To address this, the strategy will drive long-term, sustainable systemic change to how carers are valued and supported. This will help to recognise and mitigate the potential wellbeing, economic and social risks of caring. This will need immediate action as well as change over an extended period.

It is also important to build a wider understanding and recognition of caring across society. Unpaid carers are a diverse range of people covering all parts of society, but they can often be marginalised. We must ensure that unpaid care is visible, understood and valued across society, not regarded as peripheral or something that affects only particular people.

# The broader policy landscape

As part of the development of the National Care Service (NCS), we are proposing changes to how people access care and support in Scotland. People have told us that the current system of eligibility criteria often does not work for them. Eligibility criteria are focused on deficits, not outcomes, and do not necessarily put a person's human rights at the centre of decisions. We have committed to overhaul the current mechanism of eligibility criteria and set out proposals for doing this in the NCS consultation.

This will mean changing the way care and support services are designed and delivered. We want the focus to be on the support people need, not on eligibility. Prevention will be prioritised, and we will make sure that people can move easily between different types of care and support as their needs change. We will continue to actively engage with stakeholders, including carers, to develop this work. Improving access to social care cannot wait for the NCS, and we are putting in place measures to strengthen the implementation of Self-Directed Support (SDS) and improve prevention and early intervention.

The issues that affect carers go beyond health and social care. This strategy sits within a wider reform agenda, with carers at its heart. In order to achieve lasting change both for carers and the people they care for, we will drive forward a range of policy developments, such as actions to tackle health inequalities and household income. Carers' own rights and needs are impacted by the service, support or budgets available to the person they care for. This strategy will help to bring about sustainable improvements in this wider context.

We also welcome the European Care Strategy<sup>2</sup> published in September 2022which reflects the ambition to improve support and recognition for unpaid carers that Scotland and the European Union both share.

<sup>&</sup>lt;sup>2</sup> The European Commission (2022). A European Care Strategy for caregivers and care receivers - Employment, Social Affairs & Inclusion.

### The impact of COVID-19

We have learned lessons from the COVID-19 pandemic and the strategy reflects that. We know that we need to be able to support carers better whilst also enabling them to live as fully as possible.

The Scottish Government's and COSLA's jointly chaired Pandemic Response in Adult Social Care Group provided a multi-stakeholder focal point for work to support the effective delivery of adult social care during the COVID-19 pandemic. The group had a strong focus on issues that unpaid carers are experiencing, with valuable contributions from carer representatives. While the group has been superseded by new approaches to addressing social care pressures, it is vital that we continue to recognise carers and support them as we move into a new phase of living with COVID-19.

### Our approach

The strategy will cover activity during the current Scottish Parliament to spring 2026, but will be reviewed annually to monitor progress and ensure it is focussed on the most important issues.

The key themes of the strategy intend to put the individual carer at the centre and focus on five different aspects of unpaid carer support:

- Living with COVID-19
- Recognising, valuing and involving carers
- Health and social care support
- Social and financial inclusion
- Young carers

### **Developing this strategy**

We have consulted with carers with lived and living experience to ensure that in developing this strategy we have had meaningful engagement with those who know what it is like to devote a significant proportion of their time to caring for a loved one or friend. We have also engaged with carer organisations and a range of delivery partners to make sure that those who have responsibilities to support carers have also shaped this strategy.

Scottish Government policy works in a variety of ways to help protect carers' health and wellbeing and to sustain caring relationships. It is based on a human rights approach to supporting carers, in line with other government policies and legislation.

Our policies contribute to a number of outcomes from our National Performance Framework<sup>3</sup> and these principles underpin the strategy.

<sup>&</sup>lt;sup>3</sup> Scottish Government. (2022) National Performance Framework. National Outcomes.

## Carers in Scotland<sup>4</sup>

Scotland's carers make a huge contribution to the people they care for and our communities. There are more people caring full time for relatives or friends than staff working in either the NHS or in social care.<sup>5</sup> The actual number of carers is not known but it was estimated that there were 700,000 to 800,000 unpaid carers in Scotland before the COVID-19 pandemic.

### Age and gender

Of the 696,000 carers in Scotland, 28,000 are under 18.6 Although people can become carers at any stage, they are most likely to be caring between the ages of 45-54. In this age group, over a quarter of all women and around a sixth of all men are carers.

There are over 133,000 carers aged 16+ caring for 35 hours a week or more. Around a quarter of older carers (aged 65 and over) provide 35 hours of care a week or more compared with just under a tenth of carers under 24.

Overall, 59% of carers are women and 41% are men. Throughout their working years, women are more likely to be carers than men. With gender stereotypes surrounding caring still present in our society, there is a risk that women feel more pressurised to undertake caring roles. This pressure can negatively impact on a woman's career path and be a key driver of the gender pay gap.

#### **Demographic pressures**

Scotland's population is ageing, with numbers of very old people predicted to continue growing and a proportionately smaller working age population. This is a success story in terms of improved health and wellbeing and longer life expectancy, but it has significant implications for the future of care and support in Scotland. With demand for health and social care services predicted to grow by 25% by 2031<sup>7</sup>, the role and contribution of carers will be even more critical in the future.

### Intensive caring and deprivation

29% of carers in the most deprived areas care for 35 hours a week or more – more than double the level in the least deprived areas. Caring may therefore stem from lack of choice and may be exacerbated by existing inequalities of low incomes and poor health in these areas.<sup>8</sup>

#### Impacts of caring

Unpaid carers make a huge contribution to the people they care for and our communities. It is estimated that the economic value of the contribution made by

<sup>&</sup>lt;sup>4</sup> The Scottish Government (2015). <u>Scotland's Carers</u>

<sup>&</sup>lt;sup>5</sup> Information Service Division (2019). NHS Scotland National Workforce Statistics. Scottish Social Services Council (2017). Report on Workface Data.

<sup>&</sup>lt;sup>6</sup> The Scottish Government (2022) <u>Scotland's Carers Update Release</u>

Public Health Scotland (2021) <u>Population groups: older people.</u>

<sup>&</sup>lt;sup>8</sup> Hirst, M. (2005) <u>Health Inequalities and Informal Care - End of Project Report.</u>

# 1. Living with COVID-19

# Strategic outcomes

- Carers feel confident and supported to protect themselves from COVID-19.
- Carers and the people they care for feel supported and confident to re-engage with their communities.
- Carers are supported to recover from the negative impacts of COVID-19.

# Why this is important

We know the COVID-19 pandemic had and continues to have a significant effect on unpaid carers. At the start of the COVID-19 pandemic, we created carer-specific information to help carers and carer organisations find the most up-to-date information relevant for them. We worked closely with carers and carer organisations to ensure that the information met carers needs and was also circulated through channels they were likely to use. We worked with NHS 24 to develop tailored information on NHS inform for people with ongoing symptoms following COVID-19, which includes signposting to guidance and support for unpaid carers. Unpaid carers were prioritised for vaccination in line with advice from the Joint Committee of Vaccination and Immunisation (JCVI).

The pandemic enforced lockdowns and associated restrictions which presented a series of unfolding challenges for carers. Each caring situation is unique so everyone faced different situations, but we know that carers faced particular issues in caring safely and sustaining caring roles.

Many carers were supporting people who were advised to shield because they were considered to be at highest risk of becoming severely ill if they caught COVID-19. Supporting people on the Highest Risk List involved asking this group and those around them to take many extra precautions to limit the chance of catching and transmitting COVID-19. For many carers, this increased the existing stress, fear and isolation of living under lockdown and ongoing restrictions.

The majority of pandemic-related precautions have been lifted, but we have heard from some carers that they have felt vulnerable, left behind and ignored as communities, workplaces and wider society open up again. We will continue to work with carers to address their concerns and ensure they are supported to keep safe while they re-engage in their wider communities.

We recognise that some carers will be providing support to friends and family members living with long-term effects following contracting COVID-19, known as long COVID. These effects vary in their presentation and nature from person to person, and can have a significant impact for those adults and children most severely affected.

The impacts of the COVID-19 pandemic disproportionately affected different equality groups. The majority of carers are women and were at greater risk of these

disproportionate effects. Some minority ethnic groups were particularly vulnerable to COVID-19 and often less connected to support services. The pandemic increased the risk of trauma for many people across Scotland, particularly for those already affected by inequality, trauma and adversity. Research shows that experience of trauma can impact on people's mental and physical health outcomes if left unsupported.

As we move into the new phase of living with COVID-19, some carers need support to rebuild confidence and feel safe to re-engage with wider communities and services. Communication with carers is a key element of that, but there are also practical measures to share the latest guidance and expertise.

We remain committed to recognising the immense contribution carers make, increasing public awareness of caring and involving carers to ensure that our policies are informed by their lived and living experience. The following chapters set out actions to support this commitment.

"During the pandemic, the Carers Centre {CWD} provided an invaluable support whether it was an ear to listen or how to access masks, cleanser, gloves or lateral flow tests. Nothing was a problem! I cannot emphasize how helpful all concerned were. I would like to take this opportunity to thank all those people that made this possible. Thanks again."

#### How we will achieve this

- 1. Ministers and officials will continue to engage with carers to ensure their voices are heard, including ongoing support for those whose risk may still be higher.
- 2. We will continue to ensure that carers receive accurate and up-to-date information about living with COVID-19.
- 3. We will continue to closely monitor all emerging evidence on COVID-19 treatments and their clinical effectiveness.
- 4. Unpaid carers will continue to be able access free PPE until March 2023. The provision of PPE beyond this is under review.
- 5. We will continue to meet carers and carer organisations regularly to hear current concerns so we can provide up-to-date information. This includes funding and engaging with MECOPP (Minority Ethnic Carers of People Project) to ensure information meets the needs of carers with one or more protected characteristic.

- 6. We will encourage employers to be more supportive and flexible to support unpaid carers, through our Carer Positive scheme, which may include ensuring that sick pay and staffing practices support public health aims, adapting premises to make them safer for customers and staff, and enabling hybrid working where that makes sense.
- 7. We will take measures to ensure our public buildings and businesses are as safe as they can be.
- 8. We will encourage shops and other public spaces to display 'Distance Aware' signage about personal distance.
- 9. We will work with partners to raise awareness and increase the uptake of emergency and future care plans.
- 10. We will work to improve carer recognition, health and social care support, and financial and social inclusion for carers, through the actions set out in the following chapters.
- 11. We provided £21 million funding in 2021-22 and have committed £15 million funding in 2022-23 for community-based initiatives to promote good health and wellbeing and tackle the mental health issues made worse by the COVID-19 pandemic and the cost of living crisis (the Communities Mental Health and Wellbeing Fund).
- 12. As we develop Scottish Carer's Assistance, we are considering the best way to support carers to recover from the COVID-19 pandemic and future proof our benefits system to ensure there is flexibility to respond to changing circumstances.

"My daughter has long COVID – she is completely dependent on us to meet her needs. We are in our eighties – we weren't expecting this – it's so hard and we are exhausted, the services are doing all they can but she really needs round the clock care."

# 2. Valuing, Recognising and Supporting Carers

# Strategic outcomes

- Carers are recognised and their contribution is understood and valued by society.
- Carers' voices are heard and their views and experiences are taken into account in decisions which affect them.

### Why this is important

Our health and social care system could not survive without the commitment of unpaid carers. People have provided unpaid care for family and friends since before there was a health and social care system. But the way our public systems work and interact has a profound effect on the lives of those who provide unpaid care and whether caring is sustainable.

Many carers have told us that fighting their way through multiple systems is an exhausting feature of their lives, which contributes to stress. Carers can spend a lot of time trying to navigate through the system to find the right service for the person they care for or the right support for themselves. Carers have also told us that social attitudes, particularly to roles often perceived to be for women, contribute to keeping caring invisible and undervalued.

The pandemic made all of these issues worse, and for many unpaid carers, it is likely that the effects of the pandemic will continue for some time.

The Scottish Government and others responsible for developing policy and planning and delivering support or services must learn from carers' experiences and knowledge to ensure that systems are fit for purpose at a national and local level.

At an individual level, genuine communication is the key to enabling choice. Professionals need to understand and value carers' skills and insights to ensure that support for both them and the cared-for person is as good as it can be. Effective collaboration with carers includes empowering them with information about the types of support available and choices over how it is delivered. However, it is important to recognise that some carers may find it difficult to properly participate due to their own heavy caring commitments and may be excluded, especially from more intensive carer participation. Encouraging the provision of practical support to facilitate carer participation should also feature in the range of measures to support involvement.

There are already many effective processes in place to support carers, but we know that particular aspects of caring remain challenging. We will build on the existing structures that work while addressing things that need to be improved.

"I've been caring for my husband who has a diagnosis of dementia for 3 years, no-one told me there was support for me – not the doctor or the nurse who comes in. I could have done with help from the Carers Centre sooner. It's good to have it now but I've hit crisis and it's hard to pick myself up."

#### How we will achieve this

- 1. We will make it easier for people to recognise themselves as carers and to access support and advice.
- 2. We will foster a culture shift towards greater recognition and valuing carers and a connected approach to carer support across government by: connected leadership in the delivery of this strategy, ensuring carers issues are represented in the review of the National Outcomes.
- 3. We will update the Carers' Charter to reflect carers' rights to information and advice; new rights for carers of people with terminal illness; and, subject to Scottish Parliament approval, the right to breaks from caring.
- 4. We will support local carer centres to build capacity and ensure all carers can access consistent and up-to-date information.
- 5. We will keep the need for further national communications campaigns under review.
- 6. We will ensure that policy is informed by lived and living expertise, by working with carers and carer organisations to ensure carer voices are represented and heard in national policy making, including in shaping the National Care Service.
- 7. We will continue to support the Carers Parliament to engage carers in policy making and ensure their voices are heard by decision-makers. We will engage with carers to shape future Parliaments.
- 8. We will continue to support national work to engage, raise awareness and support carers' voices to be heard across all relevant issues.
- 9. We will involve carers through the Social Security Experience Panels and Social Security Scotland research, including the Client Survey and the Client Panels.
- 10. We will continue to support the Carers Collaborative and draw on reports and use this knowledge to inform future activity.
- 11. We will continue to prioritise the enhancement of carer involvement in local strategic decision making under the current system. Providing carers with support and access to national training events remains a primary focus of this work.
- 12. We will also continue to collaborate with third and independent sector bodies that enable carers in their role within integration authorities.

- 13. We will ensure that unpaid carers are involved in planning support and services under a future National Care Service through their involvement in co-design activity.
- 14. We will continue to work with partners and people with lived and living experience to make sure that our social care services work for everyone, including ensuring support for carers becomes more accessible and consistent.
- 15. We will continue to support improvement work to ensure health and social care professionals are aware of their duties to involve carers and have the skills and resources they need to work together as equal partners in care.
- 16. We will ensure that the Independent Review of Adult Social Care recommendations on effective carer involvement are delivered as a key element in a NCS.
- 17. We will continue to fund Healthcare Improvement Scotland (HIS) and NHS Education for Scotland (NES) to work in partnership and explore what 'involvement' in hospital discharge means to unpaid carers and what 'good practice' looks like.
- 18. We will improve the involvement of carers in decisions where the cared-for person has mental ill health.
- 19. We will respond to any recommendations of the Mental Health Law Review for improvements to the experience of unpaid carers, including young carers, within mental health.
- 20. We will update the Code of Practice for continuing and welfare attorneys to reflect changes in the legislative environment, taking into account UNCRPD as well as recent case law.

"I do feel listened to on the whole but sometimes I still feel that people just don't get it – how hard it is – it's exhausting."

# 3. Health and Social Care Support

### Strategic outcome

People who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact of their caring role on their own health and wellbeing. (*National health and wellbeing outcome 6*)

## Why this is important

There is a close relationship between social care support for carers and those they look after. Supporting carers in their own right improves outcomes for them and the person for whom they are caring. Sustaining caring relationships in this way has major benefits for our health and social care system. The Scottish Government will work in partnership with local government and other relevant public bodies to ensure that unpaid carers are fully supported to have a life alongside caring, in order to protect their health and wellbeing and better sustain their caring role.

There are already various ways in which we try to safeguard carers' health, including providing preventative support through the Carers Act. However, we know that many carers continue to experience a range of health problems, including poor mental health and difficulties accessing medical appointments because of their caring responsibilities. We also know that accessing social care support can be a challenge for unpaid carers, often for many of the same reasons.

The nature of some caring roles can lead to increased risks to the carer's health and wellbeing. There are a number of reasons that can give rise to this, including insufficient support for the unpaid carer, a lack of trauma-informed support from services, a lack of breaks and economic and social isolation. This can lead to poorer outcomes for the person who is being cared for.

A strategic approach is needed to tackle the causes of this kind of situation, to ensure that carers are not overwhelmed by their responsibilities and are empowered to look after their own health and wellbeing. This must be reflected consistently across the whole country to foster a balanced and sustainable lifestyle for unpaid carers.

"Thank you for remembering carers and making them remember themselves even for a little while. It allowed me to give myself permission to do something for me. I am usually the last one on the list."

## How we will achieve this

- 1. Where possible, we will increase funding to carer centres and young carer services.
- 2. We will continue to encourage authorities to spend their full share of Carers Act funding on expanding carer support, ahead of establishing a National Care Service making Ministers responsible for social care spending decisions.
- 3. We will support improvements in the data collected under the Carers Census so that only the most necessary information is collected and used to improve support for unpaid carers.
- 4. We will review and update Scotland's Carers.
- 5. We will introduce a statutory right to breaks from caring under the Carers Act and fully fund its implementation.
- 6. We will work with stakeholders to improve the availability and range of short breaks, supported by evidence to support our approach.
- 7. We will continue to work with local service commissioners, Shared Care Scotland and others to promote greater availability and choice of short break support in different areas.
- 8. We will build on our recent investment to increase funding for short break support to increase availability of easy-access preventative breaks support.
- 9. We will continue to promote the importance and regular review of Short Break Service Statements, to ensure carers understand their right to a break and the breaks available in their area.
- 10. In addition to updating the SDS Statutory Guidance, we will continue to work with and through delivery partners, including Local Authorities, to support and improve delivery of SDS consistently throughout Scotland and to support national conversations promoting improvement, early intervention, capacity-building, innovation and good practice.
- 11. In the medium-term, we will embed SDS principles and a human rights-based approach into the development of the National Care Service.
- 12. We will continue to focus on creatively and flexibly supporting carers through SDS.

- 13. We will consider how to provide flexible health appointments for carers, including how we provide replacement care for appointments.
- 14. We will continue to engage with NHS Boards to help drive implementation and support them to test and spread improvements to person-centred visiting.
- 15. We will reinforce to NHS Boards their statutory duty to involve carers in decision making about when the person they care for leaves hospital, and work in partnership to help them deliver this consistently.
- 16. We will support effective and carer-aware multi-disciplinary teams in every locality, both in and out of hours, involved in the strategic planning and delivery of services, including through the development of GIRFE.
- 17. We will consider what further resources and signposting of support may be needed to support carers' mental wellbeing within the National Wellbeing Hub.
- 18. We will work with relevant stakeholder groups to ensure that carers are aware of the range of mental health and wellbeing resources and advice available to them, and to consider whether carer-specific advice is needed.
- 19. We will share learning and examples of practice that emerge through our work on the Communities Mental Health and Wellbeing Fund projects in relation to supporting the mental health and wellbeing of carers.
- 20. We will improve training and support for health and social care professionals to help identify and support unpaid carers at risk of suicide and those who care for people at risk of suicide by promoting learning resources and awareness-raising on suicide prevention.
- 21. By spring 2023, we will publish a long-term delivery plan for the National Trauma Training Programme setting out how we will continue to support, embed and sustain trauma-informed workforces, services and care. This will include a priority focus on trauma training and support for adoptive parents, kinship, foster and supported carers to support delivery of The Promise.
- 22. We will engage widely throughout 2022/23 and co-produce with people living with dementia, carers, statutory, third sector and independent sector partners to develop our new National Dementia Strategy, building on our internationally recognised action in areas such as rights-based care and post-diagnostic support.

- 23. We will use the framework priorities to increase support for people with autism and their carers.
- 24. We will work closely with people with learning disabilities as role models, their carers and leaders to raise awareness and challenge perceptions in Scotland.
- 25. We will work with the NHS boards, integration authorities, neurological and carer organisations to help ensure carers of people living with neurological conditions are aware of their rights under the Carers Act; and that local carer services know how to access the most relevant information and training for carers of people living with neurological conditions.
- 26. We have committed £32 million of funding in 2022/23 directly to Children's Service Planning Partnerships (CSPPs) to build local service capacity for transformation and to support the scaling up of existing transformational practice of whole family support services in local areas.
- 27. We are working in collaboration with CSPPs to provide a range of support to accelerate and share learning to drive whole system change in family support at local and national level.
- 28. We have committed a further £2.974 million of funding in 2022/23 to provide support to families on a low income who are raising disabled or seriously ill children and young people through the Family Fund who deliver support, advice and direct grants to families in Scotland.
- 29. As part of the Tackling Child Poverty Delivery Plan commitment, we will engage extensively with parents, carers and children to draft a strategic framework for 'Out of School Care' by the end of this Parliamentary term.
- 30. As we design a system of wraparound childcare, we will integrate food and childcare provision wherever possible recognising the benefit to children and families of coordinating food, childcare and activities before school and during the holidays.

"Thank you so much. I have longed for a solitary trip for a long time to just be able to "step off the merrygo-round" for a day or two. I am overwhelmed with gratitude."

## 4. Social and Financial Inclusion

# Strategic outcomes

- That the social and economic contribution, impacts and scale of caring are recognised, understood and reflected in local and national policy making across all areas.
- Carers are able to access the financial support and assistance to which they are entitled.
- Carers are able to take up or maintain employment and education alongside caring if they wish to do so.
- Carers can participate in and are valued by their community and wider society.

### Why this is important

For many people who provide unpaid care it is fulfilling and meaningful. However, without proper support, the demands of some caring situations can have a negative effect on a carer's life. People can find themselves worse off financially if, for example, they are unable to work full-time because of their caring responsibilities. Some carers can also struggle to have a life beyond caring. These issues do not affect carers evenly. Women carers are more likely than men to be unable to work, with knock-on effects on their income and social isolation, while carers in remote and rural areas can face challenges related to their location.

The social security benefits available to carers recognise that caring roles can impact on people's finances. Carer's Allowance, and its forthcoming replacement in Scotland, Scottish Carer's Assistance, while not a payment for care, provides some financial support and recognition for people who have limited their employment or study because of caring responsibilities. Unlike most other income replacement benefits, there are no work requirements, and it is not means tested, but there is a limit to the amount that those who receive it can earn. For those on low incomes, the benefit can be a passport to help with other outgoings, such as housing costs.

The interaction between caring responsibilities, a person's income and their ability to maintain connections and interests in addition to being a carer is complex. Social isolation can be a particular risk for carers given the extra responsibilities they have and the financial burden that often comes with caring. If someone has to reduce the hours they work or give up work altogether, it can have a severe financial impact, and can also increase their social isolation. More is needed to ensure that carers can lead full and balanced lives and are not forced into poverty or social isolation because of their caring responsibilities. We must address the underlying reasons why so many carers find themselves in financial hardship.

Helping to ensure that carers can balance their caring responsibilities with the ability to work, attend education and have a meaningful quality of life beyond caring is crucial. The impact of the pandemic has been particularly severe for many unpaid carers, and that is being compounded by the cost crisis. This is affecting everyone, but some people face particular challenges. From engaging with carers in remote

and island communities, for example, we know they face increased barriers because of higher living costs and the greater distances to travel for caring or support.

Enabling people to provide care for their loved ones while leading rich and varied lives beyond their care responsibilities is fundamental to Scotland's wellbeing economy. It is at the heart of our Carers Strategy.

"It's a struggle managing financially especially now - I had to get a crisis loan from the Carers Centre to get food this week and I'm really worried about the summer holidays and how I am going to cope."

#### How we will achieve this

- 1. We will draw on responses to the Scottish Carer's Assistance consultation to shape future improvements to social security support for carers.
- 2. We will support people to receive what they are entitled to and work with a range of partners who have experience in benefit take-up, taking a 'lessons learned' approach on what works best.
- 3. We will run advertising campaigns to reach hard-to-reach groups and raise awareness of our benefits. We will promote our payments and remove stigma to deliver a new system that treats people with dignity, fairness and respect.
- 4. In line with our second Benefit Take-up strategy we will develop a holistic approach to signposting and referral, ensuring clients of Social Security Scotland are helped to access wider support.
- 5. We will continue to work with unpaid carers to direct them to appropriate sources of support during the cost crisis.
- 6. We will work with debt advice services and carer centres to understand and respond to the continuing impact of the rising cost of living on these services, and will ensure that the specific needs of unpaid carers are reflected.
- 7. We will draw on the findings from the Scottish Welfare Fund review to inform any future policy improvements.
- 8. We will explore a Minimum Income Guarantee (MIG) for Scotland, developed by a Steering and Expert Group, and ensure that carers' voices are integral to the design and development of the Steering Groups recommendations.

- 9. We will gather intelligence around the current range of careers information, advice and guidance and employability services to identify whether this service provision meets the particular needs of carers.
- 10. We will enhance employment support services with the aim of supporting more parents, some of whom will be carers, to enter and progress in sustainable and fair work.
- 11. We will continue to fund and promote increased uptake of the Carer Positive employer accreditation scheme, working with employers to support flexible, agile and inclusive workplaces that benefit workers with caring responsibilities.
- 12. We are providing over £750,000 in year 1 of our new multi-year Workplace Equality Fund 2022 to 2024 to overcome workforce inequalities faced by groups such as carers.
- 13. We will publish a refreshed Fair Work Action Plan, and engage with carers with lived experience of barriers to employment and employers.
- 14. We will ensure that the specific barriers faced by carers are taken account of when tackling broader societal issues such as digital exclusion and lack of access to public transport.
- 15. We will publish the Connected Scotland delivery plan in 2022.
- 16. We will extend the Connecting Scotland programme to reach up to 300,000 people by the end of this Parliament. The new delivery model will consider the needs of carers into account.
- 17. We will continue to work with COSLA to progress our shared commitment to end all charges for non-residential social care support. We will work with stakeholders to develop and implement options as soon as practicable and within the lifetime of the Parliament.

"Carers provide an invaluable service to friends and loved ones and should be celebrated. At Phoenix Group we see first-hand the important skills that working carers bring to the workplace and believe they should be supported to stay in or be able to access good work."

"Supporting carers is not just the right thing to do, it makes good business sense. It has been fantastic for Phoenix Group to participate in the Carer Positive process and we were delighted to be recognised as an Exemplary employer in 2020 due to our support for working carers. We know our colleagues really value the 10 days paid carers leave we offer to all employees every year."

Claire Hawkins, Director of Corporate Affairs and Investor Relations, and Executive Sponsor of the Phoenix Group Carers Network

# 5. Young Carers

# Strategic outcomes

- Young carers are supported and protected from inappropriate caring and negative impacts on their education, social lives and future opportunities.
- Young adult carers are supported when moving from education to training and work while balancing an ongoing caring role.

# Why this is important

Caring can be a positive experience for many young people, where they are supported to manage that role appropriately, and to have a life alongside it. Through caring, young people often develop skills and values, as well as a sense of pride and increased self-esteem from their role. There are an estimated 28,000 young carers in Scotland under the age of 18 although this is generally regarded as an underestimate. Young carers often go above and beyond what is expected of them as young people.

However, caring can also put pressure on young people, especially where they undertake inappropriate caring responsibilities or spend long hours providing care. Without the right support, young carers are at risk of negative impacts on their educational attainment, relationships with their peer group and their mental health.

Young carers often find it challenging to recognise that they have additional responsibilities. Many have grown up with caring being part of their family dynamic and these extra tasks can feel normal to them. To Sometimes families or young people will have concerns about potential negative repercussions of social work intervention. It leading to young carers actively avoiding seeking help or support.

Research also shows that young carers feel that their experiences and knowledge about the cared-for person are often overlooked by professionals, leaving them feeling excluded and undermined.<sup>12</sup> There can also be stigma associated with a younger person undertaking a caring role. Coupled with a lack of awareness or support for their caring role, this can leave young people feeling lonely and isolated.

The impact of all of these factors is that many young people who are providing care do not self-identify as a carer.

Evidence shows that young carers have poorer physical and mental wellbeing than non-carers, and are more likely to live in the most deprived areas.<sup>13</sup> Young carers also report experiences of social isolation.<sup>14</sup>

<sup>12</sup> McAndrew, Warne, Fallon and Moran (2012).

<sup>&</sup>lt;sup>9</sup> Becker (2007).

<sup>&</sup>lt;sup>10</sup> Morrow (2005); Moore and McArthur (2007); Cass et al. (2009).

<sup>&</sup>lt;sup>11</sup> Moore and McArthur (2007).

<sup>&</sup>lt;sup>13</sup> Scotland's Census (2011): 2011 census | Scotland's Census (scotlandscensus.gov.uk)

<sup>&</sup>lt;sup>14</sup> Carers Trust (2020). Protecting the Health and Wellbeing of Young Carers.

Young people aged 16-18 are often at a transition point in their lives as they finish school, get their first job, or undertake further study and training. However, opportunities that are the norm for most young people can be restricted for young carers due to the additional responsibilities and pressures that come with caring.

Throughout the COVID-19 pandemic we consulted with young carers and organisations supporting them about the issues they faced, and how best we could help them. Many young carers benefit greatly from support from local young carer services. As restrictions have been removed, young carer services are now offering a mixture of face to face and online support. We continue to work closely with service managers and the national carer organisations to ensure that these services continue to have the resources they need to do this safely.

Many of the rights, policies and opportunities laid out in the preceding chapters also apply or are available to young carers. This chapter therefore highlights policies and approaches specific to young carers which contribute to recognising, valuing and involving carers, health and social care and financial and social inclusion.

"This is my speech did in my school assembly for young carers week.

Hi my name is Addisyn i might look like a normal person but I'm special I'm a young carer.

So today I'm going to talk to you what it means to be a young carer and my day to day life looks like.

Not every day is the same I'm always looking out for my brother, i help my mum before going to school if my brother has melt downs which is most days i look after him in school when i can I'm always playing outside with him i keep him safe i help getting him ready medication try and make things fun for him try keep him calm and always explain what we are going to do.

I feel that being young carer has improved me as a person i love caring and helping others

It's given me a great opportunity to meet other young carers who also goes thru similar experience as me.

However hard it gets i would never change my brother for the world

So if you know someone who's a young carer please please show them little respect as life is not always easy thank you for your time."

#### How we will achieve this

- 1. We will continue to recognise and involve young carers as part of all of the actions highlighted in Chapter 2.
- 2. We will continue to support the Young Carers Festival where they will have the opportunity to engage with attendees and feed into future policy making.
- 3. We will continue to engage with young carers in order to improve mental health and wellbeing support.
- 4. We will work with Young Scot to develop a social media based awareness campaign to target young carers.
- 5. We will continue to provide health and social care support for young carers as part of the actions highlighted in Chapter 3.
- 6. We will continue to support work to ensure health and social care staff have the skills, knowledge and confidence to identify, support and involve young carers in line with the Carers Act.
- 7. We will continue to support work to raise awareness of young carers in schools by funding a full time Education Officer post with Carers Trust Scotland and working closely with NHS Education for Scotland.
- 8. We will help young carers secure the use of their own rights under additional support for learning legislation via the service My Rights, My Say.
- 9. We will continue to encourage uptake of the Young Carer Grant by signposting via our partner organisations.
- 10. We will continue to fund the Young Scot young carer package and have expanded this for 2022-23.

# 6. Monitoring

# Carers Strategy - implementation and monitoring

We will use the existing Carers Rights and Support Steering Group to oversee the ongoing implementation of the Strategy, extending its membership to include additional carers and other relevant organisations. We will review the Terms of Reference, membership and structure of the existing group to ensure it has sufficient influence and ambition for implementing the strategy. We will ensure that carers are directly involved in the process.

The group will be responsible for ensuring that the actions in the Strategy are implemented, monitoring their impact and ensuring that the Strategy remains relevant, particularly as we continue to learn to live with COVID-19 and manage the effects of the cost crisis.

Carers will be involved directly in measuring and monitoring the impact of the strategy during its lifespan. This will allow carers to share their experiences, measure success and advise on next steps. We will also look to engage with those carers who don't engage with formal services.

Any monitoring will be based around outcomes for carers. Improvements in carer health and wellbeing could also be captured using existing surveys as a baseline. We will seek to ensure that monitoring activity collects only the most relevant information to measure progress and inform future activity.

### Reporting

As well as monitoring our progress and measuring the outcomes of our work, it is important that we report on the progress we are making towards our targets. This will provide transparency and allow us to reassess our action plan to consider whether further or new actions are required.

### **Measuring outcomes**

As part of our co-production on the National Carers Strategy, it was agreed that we would take an outcomes-focused approach. We received feedback from a range of partners including carers, carer organisations, local government, the Third Sector, the NHS and the wider public sector.

Working with the Carers Rights and Support Steering Group and other key stakeholders, we will develop this further.

#### **Review**

We will keep this strategy under review so that we are able to respond to changing circumstances and ensure progress towards meeting the actions contained throughout.

# 7. Carer Quotes

All quotes provided by carer centres across Scotland

"Many thanks for all your support... It has been a great help receiving all your emails during covid, very informative and comforting. Many many thanks. You are doing a great job."

"I spent a very relaxing break round B&Q this afternoon and purchased my needed supply of birdie seeds etc. using your voucher. The voucher, with the help and insistence of my daughter gave me an hour away from the house and doing something I haven't been able to do for years - just wondering round B&Q - people don't realise how much a wee break like this benefits a permanent carer. Thank you again."

"When hands of time move slowly and the days merge into one another, your interest in my wellbeing provides the encouragement I need to begin again. Thank you for your constant support, the way you lift my spirit, and for checking on how I am doing, my friend whom I have yet to meet."

"A few months ago I was in a state of stress, you have helped me an awful lot. I totally feel back in control again."

"I took my three night break this week and I just want to express my thanks for organising this for me. I had such a lovely time (the resort was fantastic) and it did me the world of good to get away and to have some much needed uninterrupted sleep. So thank you."

"I just wanted to say that I think you are doing an amazing job. It could be that I have more head space to read emails and newsletters in the last couple of years, but actually I think it's more that you are offering more and more things that are useful for me, personally, in formats that are easy for me. And I am so very grateful! There's the holiday in January, the focus group with the social worker for unpaid carers, the art group during lockdown, the info about carer's legislation, links to surveys, and I'm sure I'm not remembering everything."



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