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Executive Summary

Purpose
Scotland’s carers make a huge contribution to the people they care for and our communities, but caring can impact on carers’ own wellbeing. We are committed to aligning policy to support and listen to carers.

The Carers Strategic Policy Statement (CSPS) is intended to assist local and national strategic planning and policy development to achieve that. It maps the national policies and approaches in place to support unpaid carers in Scotland. People in the public, independent and third sectors whose work affects carers can use it to make informed decisions, build connections and tap into existing opportunities.

The aim is to maximise benefit from our policies by connecting them and building a better understanding of the system as a whole. Our policies include two major reforms for carers which are key priorities for us – effective implementation of the Carers (Scotland) Act and the ongoing development of Carer’s Assistance through our new Social Security powers.

The CSPS sets out a common vision and overarching principles to guide all of these connected policies.

<table>
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</table>

Responsibility for delivering policies to support carers is shared with partners, across the statutory and third sector. Close collaboration and partnership working, with the same overall vision, outcomes and approach in mind, is vital to ensure carers receive the support they rightly deserve. The CSPS is intended to support this ambition.

Structure
The CSPS seeks to put the individual carer in the centre. It outlines what we understand about carers in Scotland (Chapter 1) and then highlights policies and approaches which affect key aspects of carers’ lives:
- Carer voice and engagement (Chapter 2)
- Health and social care support (Chapter 3)
• Social and financial inclusion (Chapter 4)

Most of these policies and approaches are relevant to carers of all ages. Policies and approaches specific to young carers are set out in a separate chapter (Chapter 5).

Each chapter sets out the overall aim (“strategic outcome”) we are working towards for carers and outlines key policies and strategies in place to try and achieve that. These policies and strategies have either been designed with carers in mind or are particularly relevant for carers. Carers are not a homogenous group so certain policies will be more relevant for some people than for others.

**Carers in Scotland (Chapter 1)**

Diagram 1: Carers in Scotland
Carer Voice and Engagement (Chapter 2)

**Strategic outcome - Carers voices are heard and their views and experiences are taken into account in decisions which affect them.**

Those responsible for planning support or services and developing policy need to learn from carers’ experiences and knowledge to ensure that systems can be fit for purpose at a national and local level. We support a variety of national forums and opportunities for carers to engage and have their voices heard, including:

- Events, such as the Carers Parliament and the Scottish Young Carers Festival
- Funding third sector partners to engage with and provide a voice for carers
- Engagement with carers on national policy development such as through the Social Security Experience Panels
- Legislation to ensure carers are involved in local strategic decision making

At an individual level, genuine communication is 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. This is reflected in:

- National Care Standards
- Legislation requiring carer involvement in individual decisions about the carer and the person they care for

We want to ensure professionals and carers have the skills and resources they need to work together as equal partners in care. Effective collaboration involves empowering carers with information about the types of support available and choices over how it is delivered and ensuring that professionals and carers understand carers’ rights to be involved in decisions about support for them and the person they care for. This is reflected in:

- The Carers’ Charter
- A range of awareness raising work with partners to implement the Carers Act

Health and Social Care Support (Chapter 3)

**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).**

Our key priority is to embed carers’ rights to support under the Carers Act. The Act aims to ensure carers have choice and control and can access preventative support to protect their wellbeing and keep caring situations manageable.

Ongoing implementation priorities and actions for the Act are set out in an implementation plan, with oversight from a cross sectoral implementation steering group.

Personalised, flexible short breaks can make a real difference for carers to recharge their batteries - helping sustain caring relationships and enabling carers to have more of a life of their own. The vital importance of high quality breaks is recognised in

- The requirement to consider short breaks under the Carers Act
- Funding for the voluntary-sector Short Breaks Fund and Respitality.
The guiding principles of personalisation and prevention will help deliver the best outcomes for individuals and the system as a whole. These principles are at the core of self-directed support as Scotland’s approach to statutory social care support. They and the Carers Act itself are also key elements of our wider work to reform adult social care to design a system fit for the future. Part of that reform work will also explore issues of charging for social care, which are often a key concern for carers.

Certain aspects of our wider health priorities are particularly important to carers:
- Our approaches to person-centred hospital visiting and to involving carers in hospital discharge will be important when the person they care for is in hospital
- Our vision for the future of primary care will benefit carers who work with and rely on multi-disciplinary teams within primary care services to support the people they care for on a day to day basis.

Our housing policies are also important. We recognise that living in the right home with the right advice and support can be the key to enabling people to live safely and independently at home. If the home of the cared-for person is suited to their needs this can make caring for them easier. This is reflected in a range of housing policies including The Technology Enabled Care Housing Charter and the refreshed housing strategy for older people.

Alongside these general policy approaches to health, social care and housing support for carers and the people they care for, our policies and strategies for supporting those with particular conditions also recognise the key role of carers. These include:
- A range of policies and programmes about support for disabled children and their families
- National Dementia Strategy
- Scottish Strategy for Autism
- Keys to Life Learning Disability Strategy
- National Action Plan on Neurological Conditions
- Rights, Respect and Recovery strategy – for families affected by substance misuse
- A range of policies and programmes about mental health support

**Social and Financial Inclusion (Chapter 4)**

<table>
<thead>
<tr>
<th>Strategic outcomes:</th>
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<tbody>
<tr>
<td>Carers access the financial support and assistance they are entitled to.</td>
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</tr>
<tr>
<td>Carers can participate in and are valued by their community and wider society.</td>
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</tbody>
</table>

Caring often brings financial impacts. Intensive levels of caring are most common in the most deprived areas. Social isolation is also a particular risk for carers. Some people give up work or reduce their hours to care, often with negative consequences in terms of financial wellbeing and social isolation.
Increasing the income of carers helps to address economic inequality as well as recognising the contribution carers make to society. Continuing implementation of our commitments to reform social security support for carers is therefore a key priority. Our new Social Security powers provide us with tools to support carers by providing them with financial support in recognition of the extra costs associated with significant caring responsibilities. This, in turn, links to the increased ability for carers to actively participate within their own communities.

In designing our newly devolved Social Security benefits, we have considered the needs of carers by drawing from their advice and lived-experience and will continue to do so with future developments and commitments.

Supporting carers to stay in or enter work also brings vital benefits to carers, employers and the economy. Although employment law is reserved to the UK Government, we are using the levers at our disposal to raise awareness amongst employers and support carers in Scotland to access and balance work and caring where possible.

A range of Scottish Government policies aim to achieve this. Some of these, like the Carer Positive accreditation scheme, are specific to carers. Many are part of the wider fair work agenda but will have particular importance for carers. Our aim is to support people into work by ensuring the employability offer in Scotland is person-centred, flexible and responsive to the needs of individuals and employers. We believe this is critical to help people access fair work and help them achieve their potential in an inclusive and fair economy.

Alongside social security and employment we want to tackle social isolation and build more carer friendly communities.

Carer friendly communities are places that reach out to support carers wherever they can by understanding caring, understanding disability and illness, and doing things differently.

And because of the risks of social isolation among carers, we are working in several ways to remove barriers to participation in training, education and employment opportunities as well as social and leisure activities. We are also implementing a transport plan which focuses on improving the door to door journeys for people with disabilities and removing the barriers which prevent them from doing so. For carers, this will assist in addressing social isolation of the people that they care for.

**Young Carers (Chapter 5)**

| Strategic outcome: Young carers are supported; and protected from inappropriate caring and negative impacts on their education, social lives and future development. |

We are clear that, for our young people, caring should not be a barrier to education, social and leisure opportunities, or accessing education or employment.

Many of the rights, policies and opportunities mentioned above are available to all carers irrespective of age, but there are often additional considerations within policy and legislation for young carers. This chapter looks at policies specifically designed
for, and available only to, young carers. These policies all contribute towards the key themes of carer voice and engagement, health and social care support and financial and social inclusion.

We recognise that young carers should be treated as young people first and foremost. As such, our policies to support young carers are designed and delivered with the principles and values embedded in the Getting it right for every child (GIRFEC) approach at the forefront. This means that all those who have a role in supporting our young people with caring responsibilities should identify and support them as young carers, along with any other need they may have.

Young carers have the same legal rights as adult carers to be involved in individual and strategic level decisions which affect them. We also support specific national level opportunities for young carers to engage and have their voices heard, including the Scottish Young Carers Festival and the social security Young Carer Experience Panel.

In terms of health and social care, every young carer has the right to a Young Carer Statement under the Carers Act and schools also play a key role in identifying and supporting many young carers. It is important to ensure a joined up approach with other, wider support for young people. Young carer rights under the Carers Act are intended to work alongside provisions such as additional support for learning and the Child’s Plan, all under the GIRFEC approach.

Much of the support for young carers is designed to allow them the chance to have the same opportunities as their non-carer peers. The new Young Carer Grant, the Young Scot package for young carers and forthcoming free bus travel will give them more opportunity to participate fully in society.

It is important that our young adults with caring responsibilities receive support when they come to make decisions about their future, including at a time of transition from school to their next positive destination. We want to ensure that they do not drop off the radar of services and that awareness of and support for their caring role is maintained once they have left school. We support a range of policies to ensure young carers can make successful transitions to further and higher education and into employment.

**Conclusion**

The CSPS sets out the Scottish Government’s policies and approaches to support unpaid carers, including our key priorities around the Carers Act and reform of carers’ social security support. It puts forward a vision, high level outcomes and common principles to tie these policies together. All this is designed to assist local and national strategic planning and policy development so that it is well informed, connected and focused on common aims – so that carers are better listened to and supported.
1. **Introduction**

1.1 **What does this document do?**

The Carers Strategic Policy Statement sets out the Scottish Government’s overall ambitions for unpaid carers and for carer support. Our priority is to make the most of two major commitments and reforms (the Carers (Scotland) Act 2016\(^1\) and ongoing reform of carer benefits) and to connect the many other reforms and initiatives which affect carers.

This document maps the main policies across the Scottish Government which will be particularly relevant to carers. It sets out the overall outcomes these policies contribute towards, as well as the principles underpinning our work.

1.2 **Who is this document for?**

The document is primarily intended to inform strategic planning and policy development for local and national organisations working with carers. It will also inform frontline workforce training, including for teachers, social workers, health professionals and carer support workers.

1.3 **Carers in Scotland\(^2\)**

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 either in the NHS or in social care\(^3\). The actual number of carers is not known but is estimated to be around 700,000 to 800,000 people. The latest estimated number of carers is 680,000\(^4\).

1.3.1 **Age and gender**

Of the 680,000 carers in Scotland, 31,000 are under 18. 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 170,000 carers aged 16+ caring for 35 hours a week or more. Over half of older carers (aged 65 and over) provide 35 hours of care a week or more compared with just over a fifth of carers under 24.

Overall, 59% of carers are women and 41% are men. Throughout the 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 pressured 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.

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Diagram 2: Carers Strategic Policy Statement Policy Map

Each thematic chapter begins with a section on “Why this is important” and “Our approach.”
1.3.2 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\(^5\), the role and contribution of carers will be even more critical in the future.

1.3.3 Intensive caring and deprivation
47% of carers in the most deprived areas care for 35 hours a week or more - almost 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\(^6\).

1.3.4 Impacts of caring
Unpaid carers make a huge contribution to the people they care for and our communities. Unpaid care in Scotland is already estimated to be worth £10.8 billion a year\(^7\).

For many people, caring can be a positive experience. Those with the least intensive caring roles can experience better than average mental health and wellbeing\(^8\). For many carers, the time spent with the person they are caring for can be a positive and rewarding experience, if supported appropriately.

However, people in more intensive and stressful caring roles often experience negative impacts on their health and wellbeing.

Carers can often go without time for themselves while they focus on providing care. Things like bringing the cared-for person to appointments, picking up prescriptions and preparing meals all take time, on top of other regular tasks such as cleaning, paying bills and shopping.

There can be additional costs associated and reduced earning capacity with a caring responsibility. Carers often have to find money for things such as specialist food and equipment or the cost of taxis where public or private transport is not appropriate or available.

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.

The level and type of care they provide is also a major factor. There are very different physical and emotional pressures from supporting someone with addiction, 

\(^5\) http://www.healthscotland.scot/population-groups/older-people
a mental illness, a physical disability or learning disability, or a progressive condition or terminal illness.

Carers’ age and wider circumstances will also play a big part in determining the impact of caring:

- Young carers have all the demands of school and growing up to contend with.
- Young adult carers can have the added pressures of moving from school into training, employment, college or university, while also making the transition from young carer support into adult carer support.
- Many adult carers try to balance their caring role with other responsibilities such as work and looking after their children.
- Older carers often have to contend with their own health problems, making some caring tasks increasingly difficult.

Where a carer’s health and wellbeing suffers, there is also an impact on the cared-for person. In turn, this often results 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.\(^9\) Where the caring role leads to a carer leaving employment, this will affect their financial situation, their employer and the wider economy.

### 1.4 Scottish Government policy and carers

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. The strategic framework below sets out the overall outcomes our policies contribute towards, as well as the principles underpinning our work.

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### 1.4.1 Strategic Framework

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<th><strong>Strategic Outcomes</strong></th>
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<tbody>
<tr>
<td>Our policies contribute to strategic outcomes across four broad areas.</td>
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</tbody>
</table>

**Carer voice and engagement**
• Carers voices are heard and their views and experiences are taken into account in decisions which affect them.

**Health and social care support**
• 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*).

**Social and financial inclusion**
• Carers access the financial support and assistance they are entitled to.
• Carers are able to take up or maintain meaningful employment alongside caring.
• Carers can participate in and are valued by their community and wider society.

**Young carers**
• Young carers are supported; and protected from inappropriate caring and negative impacts on their education, social lives and future development.

<table>
<thead>
<tr>
<th><strong>National Outcomes</strong></th>
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<tbody>
<tr>
<td>Our policies contribute to outcomes from our National Performance Framework(^\text{10}).</td>
</tr>
<tr>
<td>• We are healthy and active.</td>
</tr>
<tr>
<td>• We live in communities that are inclusive, empowered, resilient and safe.</td>
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<tr>
<td>• We respect, protect and fulfil human rights and live free from discrimination.</td>
</tr>
<tr>
<td>• We grow up loved, safe and respected so that we realise our full potential.</td>
</tr>
<tr>
<td>• We are well educated, skilled and able to contribute to society.</td>
</tr>
<tr>
<td>• We tackle poverty by sharing opportunities, wealth and power more equally.</td>
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</tbody>
</table>

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\(^\text{10}\) National Performance Framework [https://nationalperformance.gov.scot/](https://nationalperformance.gov.scot/)
1.4.2 Principles
The principles of prevention and personalisation are consistent with the Christie Commission on the future delivery of public services in Scotland\textsuperscript{11}, which described the prize for reform as a “sustainable, person-centred system, achieving outcomes for every citizen and every community”.

We aim to prioritise preventative measures across public services to reduce demand and lessen inequalities. We know that intervention at crisis point is not effective for the carer, the cared-for person or the economy. We understand that support at an early stage in a carer’s journey can prevent caring situations deteriorating.

Focusing on personalisation recognises the huge diversity of caring situations. Much of our work is founded on an understanding that enabling personalisation and choice of support leads to much better outcomes for both the carer and the cared-for person.

2. Carer Voice and Engagement

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2.1 Why this is important

Those responsible for planning support or services and developing policy need to learn from carers’ experiences and knowledge to ensure that systems can be 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 also involves empowering them with information about the types of support available and choices over how it is delivered.

2.2 Our approach

We support a variety of national forums and opportunities for carers to engage and have their voices heard. Recent legislation sets requirements for carers’ involvement in local strategic planning as well as in individual decisions which affect them. We recognise that caring roles can restrict people’s opportunities to engage and we may need to design our engagement opportunities in a different way as a result.

We want to ensure professionals and carers have the skills and resources they need to work together as equal partners in care. That involves ensuring that professionals and carers understand carers’ rights to be involved in decisions about support for them and the person they care for.

2.3 Involving carers at a national level

2.3.1 Carers Parliament

The Carers Parliament is an annual one-day engagement event for carers from across Scotland to:

- enable carers from every locality in Scotland to come together to consider, at a strategic level, the policy and legislation that affects their lives;
- influence the way forward, reflecting on the impacts of recent developments and sharing good practice; and
- ensure policymakers and politicians can hear directly from carers about their lives and the impact of policy and legislation on them.

The Parliament is funded by the Scottish Government and delivered on our behalf by Carers Scotland in partnership with a steering group of other relevant organisations, informed by carers. A report is produced and published after each Parliament to share the day with other carers from across Scotland; to assist the Scottish Government to take forward issues raised; and to help shape future Parliaments.

2.3.2 Scottish Young Carers Festival

The Festival is an annual event for young carers from across Scotland. It offers fun and respite for attendees and the opportunity for them to share experiences with peers. It also enables national policymakers and politicians to hear directly from young carers. See section 5.3.1 for more information.
2.3.3 Carer organisations
The Scottish Government funds a number of national carer organisations (NCOs) to support their work engaging with carers, raising awareness, highlighting carers’ concerns and helping provide a voice for adult and young carers in national and local decision-making. This includes the voices of carers from disadvantaged groups and different ethnic communities.

We work with these organisations, and with individual carers on a variety of carer-focused policy issues, including through the Carers Act Implementation Steering Group12 (see 3.3.2) working on our key priority to embed carers’ rights to support under the Act.

2.3.4 Adult Social Care Reform
We are working together with people who use social care support, carers, COSLA, Health and Social Care Partnerships, the social services sector, and other partners on a national programme to support reform of adult social care. As part of the People-led Policy Panel13 and through the NCOs, carers have played a central role in the development of a vision, priorities and workstreams for the reform programme. This is both in their capacity as users of social care themselves, and providers of support for people who use social care. They will continue in this important role as the programme now moves to the implementation stage.

2.3.5 Social Security Experience Panels
Scotland’s social security system is being shaped by people with direct experience of the benefits system. Since the Experience Panels14 were set up in 2017, more than 2,400 volunteers from across Scotland have shared their views and experiences. Many of these volunteers are carers. The experience panels will last for four years and will contribute to all aspects of Scotland’s new social security system. See also section 5.3.2 on the Young Carer Panel’s role in shaping the Young Carer Grant.

2.4 Involving Carers in local strategic planning
2.4.1 Local health and social care planning
The integration of health and social care support is a key priority for Scotland. Carer representatives must be included in both the governance structures of Integration Authorities and their strategic planning groups for health and social care services. This ensures carers have a voice and can influence decisions made at a strategic level, including decisions about service planning and redesign.

To support carer representatives in their roles on Integration Authorities, we fund the Carers Collaborative, which is supported through the Coalition of Carers in Scotland. This provides a forum for carer representatives to engage with their peers from other

12 https://www.gov.scot/groups/carers-act-implementation-steering-group/
13 https://www2.gov.scot/Topics/Health/Support-Social-Care/Support/Adult-Social-Care/People-ledPolicyPanel
14 Experience Panels https://www2.gov.scot/Topics/Health/Support-Social-Care/Support/Adult-Social-Care/People-ledPolicyPanel
Integration Authorities, providing support via training and networking. It also highlights good practice and common concerns to Integration Authorities\textsuperscript{15}.

2.4.2 Planning carer services
Alongside these general duties for Integration Authorities to involve carer representatives, there are also specific duties to involve carers in strategic planning under the Carers Act. Local authorities, health boards and Health and Social Care Partnerships must also involve carers and carer representatives in planning services that support carers. This includes:

- the local carer strategy, which covers carer services and plans to identify and support carers;
- local eligibility criteria for carer support; and
- ‘short breaks services statements’, to help people understand what short breaks are available locally and nationally.

2.5 Involving carers in individual decisions which affect them

2.5.1 Health and Social Care Standards
The Health and Social Care Standards\textsuperscript{16}, set out what we should all expect when using health, social care or social work services in Scotland. They explain how care and support for the carer and the person they look after should be delivered, and how they should both be involved. There is a booklet to help carers to understand the standards\textsuperscript{17}. The following standards are particularly relevant to caring situations:

- \textit{I am fully involved in developing and reviewing my personal plan, which is always available to me.}
- \textit{I am treated as an individual by people who respect my needs, choices and wishes, and anyone making a decision about my future care and support knows me.}
- \textit{If I have a carer, their needs are assessed and support provided.}

The Care Inspectorate and Healthcare Improvement Scotland consider the Standards when regulating and inspecting services. The Standards are helping to change the way health and social care support is designed and delivered, and are being used to improve the quality of services. They are also valuable to help people understand what to expect when accessing these services.

2.5.2 Decisions about social care support for carers
Health and Social Care Partnerships must involve carers in assessing their own needs for support and in deciding what support is provided and how. This is done by having a conversation with the carer to identify what is important to them in order to


\textsuperscript{17} Understanding and using the Health and Social Care Standards – A booklet for unpaid carers, 2018: https://www.gov.scot/publications/understanding-using-health-social-care-standards-booklet-unpaid-carers/
prepare an adult carer support plan or a young carer statement and then by offering the carer a choice of how any support is to be provided. See sections 3.3.1 and 3.5.1

2.5.3 Decisions about social care support for the person being cared for
Health and Social Care Partnerships must also take carers’ views into account in assessing the needs of the person being cared for\textsuperscript{18}.

2.5.4 Decisions about hospital discharge of the cared-for person
NHS Boards have a duty to involve carers in planning the return from hospital of the person they care for (or will be caring for)\textsuperscript{19}. We are supporting health boards to trial different approaches and learn from each other’s experience of delivering this new duty - to help improve patient recovery and outcomes for the carer, and reduce the risk of re-admission. This sits alongside wider ongoing work to reduce both delayed discharges from hospital and unscheduled readmission to hospital and includes the Daily Dynamic Discharge Approach\textsuperscript{20}.

2.5.5 Decisions where the cared for person has mental ill health
There are separate provisions about involving carers in decision making under mental health legislation\textsuperscript{21}. The Triangle of Care project provides a framework to support involvement of carers in the care planning and treatment for people in mental health settings. There is more information about this in section 3.11.7.

If a person is being treated under the Mental Health (Care and Treatment) (Scotland) Act 2003, the rights and views of carers must be taken into consideration as much as possible when any decisions about the service user’s care and treatment are made. Anyone involved in the care and treatment of the service user must also provide carers with the information they need to provide effective care. However, a carer will not receive any information that the service user does not want to have shared.

A service user may have a named person to help to protect their interests if they are being treated under the Mental Health Act. In the past, the primary carer would often automatically become the named person. Following changes to the law, a named person must now sign a declaration agreeing to take on the role and this must be witnessed by an appropriate person. The named person will have to be informed and consulted about aspects of care. The named person can put forward their views about the service user’s care or treatment and has a right to have their views taken account of by anyone acting under the law (for example a doctor, psychiatrist, nurse, or social worker). It is important that the service user and named person understand that they do not always have to agree and can both act independently of each other.

If a person does not have the capacity to act in their own best interests at a Mental Health Tribunal, and does not have a named person then a listed initiator can act on their behalf. Listed initiators can initiate or start applications or appeals to the Tribunal if the service user does not have the capacity to start an application by

\textsuperscript{18} Carers (Scotland) Act 2016, section 30
\textsuperscript{19} Carers (Scotland) Act 2016, section 28
\textsuperscript{21} If the patient has a suspension of detention or has received conditional discharge under the Mental Health (Care and Treatment) Act 2003
themselves. People who can be listed initiators include the primary carer and the nearest relative.

2.6 Raising awareness of carers and their rights
We have published a Carers’ Charter\textsuperscript{22}, to summarise carers’ rights under the Carers Act.

The Act also requires an information and advice service for carers in every local authority area, to help carers understand their rights and how to access support\textsuperscript{23}. In many areas, this is delivered by the local carers centre or equivalent third sector organisation.

The Implementation Plan for the Carers Act includes agreed actions to ensure that people who work in health and social care have the skills, knowledge and confidence to involve carers in decision making under the Act. There is more information about that plan in Section 3.3.2.

The Carers Act Implementation Steering Group has agreed that the aims of the Carers Act cannot be realised without greater public awareness of caring and carers’ rights to support. National carer organisations already have a focus on awareness raising, while statutory agencies and carer centres play a key role locally. To build on this, we will undertake a national marketing campaign next year to help more people recognise when they may be a carer and that carers have rights to support.

\textsuperscript{22} Carers’ charter https://www.gov.scot/publications/carers-charter/
\textsuperscript{23} Carers (Scotland) Act 2016, section 34
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)*

#### 3.1 Why this is important

A great many people in Scotland already rely on the support of unpaid carers, who make a major contribution to our social care system. Demand for social care support is growing faster than our traditional services were designed for. In this context, the role and contribution of carers will be even more critical in the future. This is why the reform programme for adult social care is required to adapt current models of service and support to meet the new levels of need and complexity.

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 they are caring for. Sustaining caring relationships in this way has major benefits for our health and social care system.

#### 3.2 Our approach

Our continuing priority is to embed carers’ rights to support under the Carers Act. The need for high quality breaks to benefit both parties is important to our approach to supporting carers, both under the Act and through the voluntary-sector Short Breaks Fund.

The guiding principles of personalisation and prevention (see Chapter 1) will help deliver the best outcomes for individuals and the system as a whole. These principles are at the core of self-directed support as Scotland’s approach to statutory social care support. They and the Carers Act itself are also key elements of our wider work to reform adult social care to design a system fit for the future. Part of that reform work will also explore issues of charging for social care, which are often a key concern for carers.

Many aspects of our wider health priorities are also relevant to carers. Our approaches to person-centred hospital visiting and to involving carers in hospital discharge will be important when the person they care for is in hospital. On a day to day basis, carers work with and rely on multi-disciplinary teams within primary care services to support the people they care for. So carers will benefit from our vision for the future of primary care, which is intended to deliver change to better meet evolving needs and demands.

We recognise that if an intensive caring role goes on too long without support it can lead to increased risks to the carer’s health and wellbeing and can give rise to risks associated with the person that they care for. Our approach is that we promote the support and protection of people to keep them well and safe from harm.

Our housing policies are also relevant for carers. We recognise that living in the right home with the right advice and support can be the key to enabling people to live safely and independently at home. If the home of the cared-for person is suited to their needs this can make caring for them easier.
Alongside these general policy approaches to health, social care and housing support for carers and the people they care for, our policies and strategies for supporting those with particular conditions also recognise the key role of carers.

### 3.3 Carers Act

#### 3.3.1 Carers Act – overview

The Act took effect in April 2018. It puts in place a system of carers’ rights designed to listen to carers; expand and transform carer support; and prevent problems – helping sustain caring relationships and protect carers’ health and wellbeing.

This includes each carer’s right to a personalised plan (an adult carer support plan or young carer statement) to identify what is important to them, for example, returning to work or undertaking studies or training. The plan will also identify carers’ needs for support and contain information about:

- the nature and extent of the care provided and the impact on the carer’s wellbeing and day-to-day life;
- the extent to which the carer is able and willing to provide care;
- emergency and future care planning.

Carers have the right to support to meet their eligible needs. Local authorities must consider whether that support should include a break from caring and record these decisions in the plan.

We have already developed extensive guidance and resources and invested through local authority budgets to support local implementation.

#### 3.3.2 Strategy and leadership

Given the scale of change involved, we recognise the long term commitment and partnerships needed to ensure the Act delivers the full benefits to carers.

That is why we are working with the Carers Act Implementation Steering Group bringing together carers, carer organisations, COSLA, health and social care partnerships and others to support and guide implementation. The group has developed a national plan for implementing the Carers Act. The plan covers six key priorities including workforce development; awareness and communications; and measuring progress and impact.

#### 3.3.3 Workforce

Some of the key actions under the national plan for implementing the Carers Act are to ensure people who work in health and social care and education have the skills, knowledge and confidence to identify, support and involve carers in line with the Act.

The Scottish Social Services Council (SSSC) is also working on the design of social work frameworks with a focus on carers’ rights. This will involve input to the Post Qualifying Standards for Social Work, as well as an assessment model for the

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Standards. SSSC also developed a ‘Personal Outcomes Planning eBook’\textsuperscript{25} to support practitioners undertaking adult carer support plans and young carer statements.

3.3.4 Third sector
We recognise that third sector organisations have a central role in delivering local carer support. We have funded the Coalition of Carers in Scotland to help local carer support organisations build capacity to deliver under the Carers Act and strengthen collaboration between these local carer organisations and their statutory partners. Through the Scottish Council for Voluntary Organisations, we have provided small grants to help local carer organisations across Scotland update their resources, technology and systems to gear up for the Carers Act\textsuperscript{26}.

3.3.5 Measuring progress
We acknowledge the need to measure progress and impact of the Act, through the support provided locally. The ‘Carers Census’\textsuperscript{27} is collecting information from the local integration authorities and carer organisations with responsibility for implementing the Act. It aims to establish the number of carers receiving support and what that support looks like, as well as an overview of progress across the country.

3.4 Breaks from Caring
3.4.1 Carers Act
Personalised, flexible short breaks can make a real difference for carers to recharge their batteries - helping sustain caring relationships and enabling carers to have more of a life of their own.

Local authorities and integration authorities have a specific duty to consider whether support to a carer should include a break from caring\textsuperscript{28}. We have funded the Short Breaks Market Shaping Think Tank - an action learning project developed in partnership with Shared Care Scotland and iHub - to explore and develop strategies for shaping local markets of short break provision. They will produce a blueprint that can be shared with others involved in shaping sustainable markets in social care.

Integration Authorities also have a duty to develop and publish a Short Breaks Services Statement - to help people understand what short breaks are available to them locally and nationally. The information must be accessible to, and proportionate to the needs of, the persons to whom it is provided (see section 2.4.2).

3.4.2 Innovative approaches to short breaks
Alongside statutory obligations under the Carers Act as outlined above we provide a £3 million non-statutory fund to make a range of short breaks available through the third sector. The Short Breaks Fund is provided on a rolling annual basis through

\footnotesize{\textsuperscript{25} Personal Outcomes Planning eBook http://learn.sssc.uk.com/course/view3234.html?id=90  
\textsuperscript{26} CATS Fund https://scvo.org.uk/running-your-organisation/funding/carers-act-transformation-support-fund  
\textsuperscript{27} Carers Census https://www2.gov.scot/Topics/Statistics/Browse/Health/DataSupplier/CarersData  
\textsuperscript{28} Carers (Scotland) Act 2016, section 25}
four programmes designed to provide preventative breaks for carers alongside (and not in place of) statutory support.

3.4.2.1 Better Breaks
This programme\(^{29}\) provides 12 month grants to third sector organisations to develop and deliver short breaks projects and services for children and young people with disabilities (aged 20 and under), and their carers (adult carers and/or young carers).

3.4.2.2 Creative Breaks
This programme\(^{30}\) provides 12 month grants to third sector organisations to develop and deliver short breaks projects and services for carers of adults (aged 21 years and over), carers of older people (aged 65 years and over), young carers (caring for children or adults), and those that they care for.

3.4.2.3 Time to Live
This programme\(^{31}\) provides grant funding to carers organisations (usually carers centres) to develop and deliver micro grant schemes for carers of adults (aged 21 years and over), carers of older people (aged 65 years and older) and young carers. Time to Live enables carers to access funds and support to help them take short breaks that meet their needs.

3.4.2.4 Take a Break Scotland
This programme\(^{32}\), provides direct grants to families of children and young people with disabilities to support personalised leisure activities or holiday breaks.

3.4.2.5 Respitality
Alongside the Short Breaks Fund programmes, Respitality\(^{33}\) (respite+hospitality) which is delivered by Shared Care Scotland through funding from Scottish Government, encourages carers centres to build relationships with local businesses, such as hotels, B&Bs, restaurants and other leisure providers, resulting in the donation of a range of gifts, breaks and experiences to unpaid carers in the area free of charge. Hospitality and leisure organisations recognise the benefits of becoming carer aware and helping to promote their business in their own community. This provides carers with different break options and the potential for these one-off breaks to be a stepping stone into them accessing breaks regularly.

3.5 Options and decision making about social care
3.5.1 Self-directed support - overview
Self-directed support is Scotland’s approach to social care support. It allows people and their carers to make informed choices on what their support looks like and how it is delivered. Greater control of their life and decision making leads to better health and wellbeing for carers and supported people. Self-directed support applies across all ages and user groups, including children and young carers.

\(^{29}\) Short Breaks Fund https://www.sharedcarescotland.org.uk/shortbreaksfund/betterbreaks/
\(^{30}\) Creative Breaks programme https://www.sharedcarescotland.org.uk/shortbreaksfund/creativebreaks/
\(^{31}\) Time to Live programme https://www.sharedcarescotland.org.uk/shortbreaksfund/timetolive/
\(^{32}\) Take a Break Scotland https://takeabreakscotland.org.uk/
\(^{33}\) Respitality https://www.sharedcarescotland.org.uk/respitality/
For carers, a good experience of self-directed support can contribute to a life beyond caring for themselves and the person they look after. This can mean being able to participate in their communities and make informed and supported choices about their life.

The Social Care (Self-directed Support) (Scotland) Act 2013 requires local authorities to offer people who are eligible for social care a range of choices over how they receive their support. Self-directed support offers options to ensure everyone can exercise choice and control including:

- A direct payment;
- Funding given to a provider of your choice;
- The council/Integration Authority can arrange a service for you; or
- You can have a mixture of these options for different types of support.

Self-directed support is important for carers both in relation to support for themselves and support for the person they care for.

3.5.2 Self-directed support for the cared for person
The statutory guidance for the Carers Act makes it clear that carers should be involved in assessment for self-directed support options and decision-making for the supported person where appropriate.

This may involve a carer assisting the person they care for in decision making. The statutory guidance which accompanies the Social Care (Self-directed Support) (Scotland) Act 2013 refers to the principles of supported decision-making in paragraph 7.23, ‘Assistance with Decision making and Understanding’. Further guidance can be found in the Mental Welfare Commission for Scotland Good Practice Guide Supported Decision Making.

3.6 Charging for social care support
3.6.1 Support for carers
Carers should not be charged for carer support under the Carers Act. This is because the Carers (Waiving of Charges for Support) (Scotland) Regulations 2014 and the Self-directed Support (Direct Payments) (Scotland) Regulations 2014 require local authorities to waive charges for support provided to carers.

The statutory guidance for the Carers Act includes guidance on this. The Scottish Government, COSLA and social care practitioners have worked together to develop a series of examples to help with interpretation of these rules.

3.6.2 Charging for adult social care
Personal and nursing care in Scotland is free for anyone who is assessed as eligible by their local authority, to receive this service, regardless of their age, income or

34 http://www.legislation.gov.uk/asp/2013/1/contents/enacted
37 https://www2.gov.scot/Topics/Health/Support-Social-Care/Unpaid-Carers/Implementation/Guidance
circumstances. People may still be charged for adult social care support that is not classed as personal care. Charges for social care support are dependent on a financial assessment also carried out by the local authority which is means tested. The three main areas in relation to adult social care and charging are free personal and nursing care; residential care and non-residential care.

3.6.2.1 Free personal and nursing care
The Free Personal and Nursing Care guidance\(^{38}\) sets out the framework of access to free personal care and/or nursing care to any adult who is found eligible by their local authority as needing both or either of these services. This guidance outlines the implementation of free personal and nursing care for those receiving care at home and for those living in a care home. Personal care services include personal hygiene such as bathing, showering and shaving or help with food preparation.

3.6.2.2 Residential care charging
The Charging for Residential Accommodation Guidance (“CRAG”)\(^{39}\) provides the framework for local authorities to charge for the residential care that they provide or arrange. This statutory guidance is updated annually.

3.6.2.3 Non-residential care charging
The Convention of Scottish Local Authorities (“COSLA”) provides the non-statutory National Strategy & Guidance – Charges Applying to Non-residential Social Care Services\(^{40}\). This guidance provides a framework that aims to maintain local accountability and discretion of local authorities when charging for non-residential social care services. This guidance is also updated annually and issued to local authorities. Examples of things that are not classed as personal care and that can be potentially charge for include community meals, lunch clubs, day care, community alarms and help with shopping or housework.

3.6.3 Children’s services – charging
Children are not charged for any social care support (either personal or non-personal) up to the point that they transition from children’s social work services to adult social work services, which can be at any point between their 16th and 18th birthdays for children not looked after by local authorities.

3.7 Reform of adult social care support programme
The reform programme is based on the expertise and experiences of people who use social care support, carers, and those who work in the sector. It has followed a co-production process to develop a shared vision of what adult social care support will look like in future, and a set of priorities for making the changes required to achieve this.

\(^{38}\) https://www.sehd.scot.nhs.uk/publications/CC2018_03.pdf
\(^{39}\) CRAG https://www.sehd.scot.nhs.uk/publications/CC2019_03.pdf
The programme’s priorities\(^{41}\) include: a shared agreement on the purpose of adult social care support, with a focus on human rights; social care support that is centred on a person, how they want to live their life, and what is important to them – including the freedom to move to a different area of Scotland; and investment in social care support, and looking at how it is paid for in the future.

The programme includes a refreshed implementation plan for self-directed support. This plan contains actions to support and build on progress made in local areas to date towards more flexible and responsive social care support, co-produced with communities and supported people.

The programme will support change through a set of workstreams that will focus on particular elements. Carers may be particularly interested in the plans for:

- The purpose and value of social care support and self-directed approaches
- Consistent experience and expectations
- Models of care and support
- Investment in care and support

Carers often raise the cost of care and how it is paid for as an issue. Exploring this together will be a key part of the programme. Together, we will consider alternative models for funding care and support that will support us to achieve our aims for health and social care support into the future. This includes a proposal for a potential new national scheme to provide extra financial support to people with the highest social care support needs. In turn, this could make a significant difference to the support that carers receive in these caring situations.

Our models must enable investment at both ends of the scale – in high-end care and support needs, and in low-level and preventative support.

### 3.8 Caring roles and protecting people

If an intensive caring role goes on too long without support it can lead to increased risks to the carer’s health and wellbeing and can give rise to risks associated with the person that they care for.

In situations where the caring situation is causing harm to the carer’s wellbeing or that of the cared-for person, it may be necessary to provide additional support and in some cases to raise an adult support and protection\(^{42}\) concern in line with local multiagency adult support and protection guidelines. See also section 5.4.2 on Keeping young carers safe from harm.

\(^{41}\) Adult Social Care Reform [https://www2.gov.scot/Topics/Health/Support-Social-Care/Support/Adult-Social-Care](https://www2.gov.scot/Topics/Health/Support-Social-Care/Support/Adult-Social-Care)

\(^{42}\) Adult protection policy: [http://www.gov.scot/Topics/Health/Support-Social-Care/Adult-Support-Protection](http://www.gov.scot/Topics/Health/Support-Social-Care/Adult-Support-Protection)
3.9 Carers and the NHS

3.9.1 When the cared-for person is in hospital

3.9.1.1 Visiting hospital

Hospital visiting arrangements are very important for carers when the person they care for is in hospital. We are working with NHS Boards to implement person-centred visiting across Scotland.

Person-centred visiting shifts most of the control over visiting to the patient and their immediate family, much like the arrangements commonplace in children’s hospital settings. It is a partnership approach between patient, carers and clinical staff to ensure people stay connected, on their terms, to the people that matter most to them.

Organisations which have developed a patient and carer friendly culture which puts visiting under the control of the individual and their carer have demonstrated wider impact on safety and effectiveness. Positive impacts include reductions in falls and complaints, as well as improved patient and carer experience. There is growing evidence of the benefits of allowing people better access to carers while they are in hospital, for patients as well as staff and the Programme For Government43 2018-19 contains a commitment to person-centred, flexible visiting across our NHS by 2020.

There are already good examples of flexible, person-centred visiting across Scotland. We are engaging with Boards to help drive implementation and supporting them to test and spread improvements to person-centred visiting.

3.9.1.2 Leaving hospital

As highlighted in Chapter 2, NHS Boards have a statutory duty to involve carers in decision making about when the person they care for leaves hospital.

We are working with NHS Education Scotland and the Scottish Social Services Council to refresh the Equal Partners in Care44 (EPIC) resource and to evaluate projects in health boards exploring approaches to involve carers in the decisions around the hospital discharge of the person they care for. This should lead to more successful discharges with carers who are better equipped to care for the person once they leave hospital.

3.9.2 Primary Care and GPs

Primary care is the first point of contact with the NHS and is where around 90% of all health contacts in Scotland take place45. Primary care is often made up of multi-disciplinary teams including General Practitioners (GPs), community nurses, dentists, pharmacists, allied healthcare professionals, social workers, social care staff, the voluntary sector and other specialists.

45 http://www.nhresearchscotland.org.uk/research-areas/primary-care
Carers rely on many of these services on a day to day basis to support the people they care for. These services are also well placed to identify carers and put them in touch with sources of carer support. This section highlights particular opportunities.

### 3.9.2.1 Vision for Primary Care

The Scottish Government’s vision for the future of primary care services is for these multi-disciplinary teams to work effectively together to support people in the community and free up GPs to spend more time with patients in specific need of their expertise. We are already working to transform primary care in order to develop new ways of working that will help to put in place long-term, sustainable, integrated change to better meet evolving needs and demands. This includes:

- Putting general practice and primary care at the heart of the healthcare system.
- Ensuring people who need care are more informed and empowered than ever, with access to the right person at the right time, and remaining at or near home wherever possible.
- Developing multi-disciplinary teams in every locality, both in and out of hours, involved in the strategic planning and delivery of services.

### 3.9.2.2 Pharmacies

The community pharmacy network is located at the heart of our communities and provides a range of pharmaceutical care and support to patients and their carers. The pharmacy team has a unique and specialist knowledge of medicines and is well placed to support carers with advice on the safe use of medicines and to help self-manage any care needs.

In some cases young carers may be responsible for collecting prescribed medicines from the community pharmacy on behalf of the person they care for. It is important that the pharmacist and the pharmacy team help and advise the young carer in the safe use of medicines.

### 3.9.2.3 GP receptionists

As part of the Scottish Government’s vision of primary care, the role of the GP receptionist is evolving. As part of their new care navigation role, the receptionist will have a conversation with the patient or carer to establish what the problem might be in order to support the patient to see the right clinical professional.

This approach values the carer’s knowledge of the cared-for person’s condition and support better health outcomes. If the carer presents as a patient in their own right at the GP practice, then their own needs will be captured as part of these conversations, and the receptionist would direct the carer to the appropriate support.

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46 Primary Care outcomes [https://www2.gov.scot/Topics/Health/Services/Primary-Care/PrimaryCare-Outcomes-Framework](https://www2.gov.scot/Topics/Health/Services/Primary-Care/PrimaryCare-Outcomes-Framework)

3.9.2.4 **Community link workers**

The Scottish GP Contract, introduced last year, expands the multi-disciplinary team that supports GPs to improve patient care and reduce GP workload. We are investing to increase the number of other health professionals working in primary care.

As part of this reform, we committed to increasing the numbers of community link workers (CLW) by at least 250 by the end of this parliament. A CLW is a generalist practitioner based in or aligned to a GP practice or Cluster who works directly with patients to help them navigate and engage with wider services. Their purpose is to improve patient health and wellbeing, reduce pressure on general practice and tackle health inequalities.

A CLW offers non-clinical support to patients, enabling them to set goals and overcome barriers, in order that they can take greater control of their health and wellbeing. They support patients to achieve their goals by enabling them to identify and access relevant resources or services in their community. A CLW also maps local services, engaging with and developing productive relationships with these services including keeping informed of the status of existing and new services.

A CLW’s knowledge of local services should include knowledge of local carer organisations and support, which will be dependent on the local area and the needs of the individual. Currently, CLW’s are targeted in areas of deprivation. Sometimes caring can arise from a lack of choices and exacerbated by inequalities of low incomes and poor health.

3.9.2.5 **Flu vaccinations**

Adult and young carers are entitled to free seasonal flu vaccination between October and March from their GP to protect them and the people they care for from the effects of seasonal flu. Carers should contact their GP to book an appointment.

3.10 **Carers and Housing**

The Scottish Government champions independent living for older and disabled people within their communities. Living in the right home with the right advice and support can be the key to enabling people to live safely and independently at home. If the home of the cared-for person is suited to their needs this can make caring for them easier.

3.10.1 **Housing Strategy**

Age, Home and Community – The Next Phase48, is Scotland’s refreshed housing strategy for older people. It reflects changing needs and demand, demographics and looks to address issues of isolation older people can face as well as improving access to suitable housing. Carers who care for older people can also face issues of isolation if the intensity of caring is high or they live remotely.

3.10.2 Fairer Scotland for Disabled People Delivery Plan
Our Fairer Scotland for Disabled People Delivery Plan sets out a number of housing related actions. For example we have recently published new practical guidance for local authorities that will support the delivery of more wheelchair accessible housing. For carers, good accessibility of a home can make a huge difference and reduce injuries from inappropriate manual handling.

3.10.3 Adaptations
Adaptations such as a level access shower or stair lift can improve safety, dignity and wellbeing of both the individual and the carer. Integration Authorities are responsible for the planning and commissioning of services to improve outcomes for people who require adaptations, and Health and Social Care Partnerships are responsible for the delivery of those adaptations.

3.10.4 Technology enabled care
Technology enabled care (TEC) in the home can help individuals live with greater independence and have a positive impact on the carer. The Technology Enabled Care in Housing Charter has been developed to support and underpin the use of TEC in creating and delivering housing solutions. It has seven pledges including taking account of people’s needs and putting them and their carers at the heart of the co-design, testing and review of services, to enable people to live in their homes safely and independently, for as long as possible.

3.11 Carers and policies/strategies focused on particular care groups
As discussed in the introduction, the issues carers face will be strongly linked to their caring situation and significantly the cared-for person’s condition. Any successful support for the cared-for person often relies on the carer’s expertise and understanding of their condition. An increasing number of our strategies for different situations and conditions therefore include a focus on working with carers.

3.11.1 Supporting Disabled Children, Young People and their Families.
Caring for a child with a disability can be both rewarding and also bring challenges in relation to the social care support as the child ages. The Scottish Government has identified three priority areas to support disabled children, young people and their families. This is to ensure they get the right support, at the right time, and in the right way from birth to adulthood.

We have published an online resource, Supporting disabled children, young people and their families: guidance, which concentrates on these priorities. The resource has been developed to ensure that children, young people and their families/carers:

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51 https://www.gov.scot/publications/adaptations-aids-equipment-advice-note/
52 Technology Enabled Care in Housing Charter https://techousing.co.uk/the-charter-pledges/
• are more aware of the support available nationally and locally and understand their rights, what their entitlements are and how to realise them;
• have improved access to support and services, by providers ensuring their needs are identified quickly and they receive the support that is right for them;
• receive the right support and services at key points of transition, in particular when transitioning from children to adult services.

A particular challenge that is often raised by family carers is when young people with disabilities make the transition into adult service provision. If this is not managed well, it can have a profound impact on the health and wellbeing of not just the child but also the family carers. The roles of education and social work alongside health are key to ensuring a successful transition from children’s services to adult services. Often other agencies play an important role as well including the third sector.

3.11.1.1 Family Fund for families with disabled children
The Scottish Government currently funds Family Fund £2.983 million annually to support low income families raising disabled and seriously ill children and young people. This is to ensure that they have the same opportunities as other children, by supporting their carers with the extra costs this may incur. The fund provides grants for essential items such as kitchen appliances, clothing, bedding, sensory toys, computers and tablets, as well as much-needed family breaks and more.

3.11.1.2 Out of School Care
Out of School Care encompasses breakfast clubs, after school clubs, holiday schemes and childminders. It is mainly aimed at primary school children, although some secondary school children also use these services.

Available evidence on Out of School Care highlights links to child poverty. Access to affordable and accessible childcare for school-age children presents a barrier to parents taking up or retaining good quality employment. We know that parents and carers who have children with a disability or additional support needs can find it more difficult to access appropriate services than other families.

The Children (Scotland) Act 1995 places a statutory duty on local authorities to provide daycare for school age children “in need” both before and after school and during holidays. “In need” is defined as ‘being in need of care and attention because, amongst other things, the child may have ill-health or a disability, or because they are affected by a disability of a family member. This legislation may therefore be particularly relevant for carers who care for a child with a disability or for those children who care for a disabled relative.

The Tackling Child Poverty Delivery Plan commits to developing new Out of School Care support to help low income parents reduce childcare costs, work more flexibly

56 Children (Scotland) Act 1995, section 27
57 Children (Scotland) Act 1995, section 93(4)
and increase their incomes. We are engaging extensively with parents, carers and children to draft a strategic framework for Out of School Care by the end of this Parliamentary term.

3.11.1.3 Out of School Care Fund
We have created a £3 million 2 year fund for delivering community based childcare and activities which will help to reduce the cost of living for low income families by providing subsidised or low cost childcare for school aged children.

Each project should be able to demonstrate direct positive impacts for at least one of the 6 priority groups identified in the Tackling Child Poverty Delivery Plan and also demonstrate positive outcomes for children, including those “in need”.

3.11.2 National Dementia Strategy
Scotland’s National Dementia Strategy 2017-2020 sets out national action to support better services and supports for people with dementia and their carers. Key areas include more and earlier diagnoses, increasing access to support after diagnoses, improving integrated home care and taking a national approach to dementia palliative and end of life care. Like the two predecessor strategies, it has a specific focus on supporting and enabling family carers of people with dementia.

In particular, the Standards of Care for Dementia provide human rights-based standards that people with dementia and their carers can expect across all care settings. There is a specific standard that people with dementia have the right to have carers who are well supported about dementia. Carers are entitled under the standards to be involved in all aspects of care planning (see also section 2.5) to be well informed about dementia and to access appropriate peer support. We fund two national dementia workforce programmes to support local implementation of the dementia standards.

In addition, everyone newly diagnosed with dementia is entitled to at least a year’s dedicated post-diagnostic support, coordinated by a named Link Worker. The Link Worker works with the person with dementia and their carer(s) to understand the illness, plan earlier for future care options and build a personalised care plan.

The Scottish Government provides funding support for two national dementia carer groups, which are involved in developing and implementing the strategy – including informing workforce development and services modernisation.

During the course of 2019/20, we will engage widely, including with service users and carers and statutory, third sector and independent sector partners to develop our fourth National Dementia Strategy, building on our internationally recognised action in areas such as rights-based care and post-diagnostic support.

3.11.3 Scottish Strategy for Autism
Scotland’s National Autism Strategy Outcomes and priorities for 2018-2021 sets out priorities for action to improve outcomes for autistic people and their carers living in Scotland. The outcomes were developed following engagement with autistic people, carers and professionals. The document sets out our priorities to ensure that autistic people can live a healthy life; have choice and control; are able to live independently; and be active citizens by participating in all aspects of community and society. For carers it is vital that we create a society that works for autistic people that they care for.

Our autism outcomes and priorities strategy emphasises the joint commitment of national and local Government to autistic people and their carers. The framework sets out a range of priorities which will increase support for people with autism, which in turn helps carers and improve public understanding of the condition. These priorities include improving the diagnosis process and care pathway for autism. We will be working with Scottish Autism to improve the support given to newly diagnosed autistic people and their carers. Carers will be made aware of the blue badge scheme and encouraged to apply for it.

In addition, we will continue work with Education Scotland to refresh the autism resource available to all schools. The framework will also include having a national autism awareness campaign.

3.11.4 The Keys to Life – Learning Disability Strategy
The Scottish Government is committed to improving the lives of people with learning disabilities and supporting their carers. In 2019, we published, with COSLA, a new joint framework to support the delivery of our ‘Keys to Life’ learning disability strategy. This implementation framework sets out how to meet the strategy’s goals for people with learning disabilities in Scotland.

The framework sets out our priorities to ensure that people with learning disabilities can live a healthy life; are treated with dignity and respect; are able to live independently; and participate in all aspects of community and society. Everyone with a learning disability should have the opportunity to shape their own lives and deliver on their potential. For carers, adequate support needs to be available at the right time and right place to allow them to continue their caring role.

The framework is an important step towards this. It is vital that people with a learning disability are listened to and supported to make choices about how they want to live their lives. In taking forward the new framework, we will be working closely with people with learning disabilities as role models, their carers and leaders to raise awareness and challenge perceptions in Scotland. The framework also emphasises the joint commitment of national and local Government to people with a learning disability and their carers.

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3.11.5 National Action Plan on Neurological Conditions
It is estimated that there are around one million people in Scotland living with a neurological condition, of whom at least 10% are disabled as a result. This Plan for 2019-2024 sets out a vision for driving improvement in the care, treatment and support available to people living with neurological conditions – and their carers - in Scotland. Its vision is that ‘Everyone with a neurological condition will be able to access the care and support they need to live well, on their own terms.’ An aim is to ensure people with neurological conditions and their carers are partners in their care and support.

In order to help deliver this, the Plan includes a commitment to work with the NHS, 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
• Local carer information and advice services know how to access the most relevant information and training for carers of people living with neurological conditions.

3.11.6 Families affected by substance misuse
The national strategy, Rights, Respect and Recovery (2018) outlines commitments to support not only treatment options for drug and alcohol use but also support for those living with or affected by this. This strategy sets out a shift towards a whole family and family inclusive practice approach to treatment, with lived and living experience at the heart.

We know it is most often the families who are there 24/7 as the first point of contact, caring for a family member or a friend affected by drug and/or alcohol use, coping with very challenging situations. This includes kinship carers, often grandparents looking after grandchildren as well as dealing with their own adult child’s alcohol or drug use.

Our key commitments include ensuring family members, including those who are carers:
• will have access to support in their own right, and where appropriate included in the cared-for person’s treatment and support
• are involved in the planning, development and delivery of services at local, regional and national level; and
• will have access to services (both statutory and third sector) provided through a whole family approach in line with GIRFEC values and principles. The whole family approach explores tailored support for all that are affected, including carers of people affected by substance use.

3.11.7 Mental health support

Mental illness is one of the major public health challenges in Scotland. Around one in three people are estimated to be affected by mental illness in any one year. Improving mental health is a priority for the Scottish Government.

We want to make it easier for those caring for people with mental ill health to make informed decisions by improving the information and support available. We will enhance the ‘111’ telephone service which provides urgent health advice out of hours, to better support carers. We will also make online information more easily available.

Sometimes people with mental ill health require additional support to help them make informed decisions using supported decision-making. This can refer to any process in which an individual is provided with the support they need in order for them to be able to make a decision for themselves and or express their will and preferences within the context of substitute decision making e.g. guardianships or compulsory treatment for mental illness or informally, in family relationships for example. The purpose of supported decision-making is to ensure that the individual’s will and preferences are central to and fully respected in decisions that concerns them. In supporting a person to make decisions, carers will have to continuously work to do ‘the right thing’, disregarding their own needs and preferences in favour of those expressed by the decision-maker.

The Scottish Government will improve the way mental health services support carers for example through developing community services for 5 to 24 year olds to provide direct and immediate access to counselling sessions, not only for children and young people, but also their families and carers.

We also fund the Triangle of Care project, delivered by Carers Trust Scotland. It provides a framework with resources and training to support mental health professionals to involve carers in the care planning and treatment for the cared-for person in mental health settings. The main Triangle of Care resources are being refreshed and will be ready around November 2019.

The approach of the Triangle of Care is equally relevant and appropriate for Child and adolescent mental health services (CAMHS) and adult mental health services. Therefore Carers Trust Scotland will develop a new resource to supplement the main Triangle of Care resources to help mental health professionals in CAMHS to better identify, understand and support carers. The new resource will also be designed to be useful for carers, families and young people using CAMHS. It is intended that the

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resource will help carers understand how CAMHS staff should engage with them and value their caring role and the importance of partnership working.

A new CAMHS assessment tool has also been developed, heavily based upon the main Triangle of Care self-assessment tool, enabling CAMHS teams to get a true picture of how they engage with carers and families, supporting them to create action plans to improve.
4. **Social and Financial inclusion**

<table>
<thead>
<tr>
<th>Strategic Outcomes</th>
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<tr>
<td>Carers access the financial support and assistance they are entitled to.</td>
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<tr>
<td>Carers are able to take up or maintain meaningful employment alongside caring.</td>
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<tr>
<td>Carers can participate in and are valued by their community and wider society.</td>
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4.1 **Why this is important**

We recognise that intensive levels of caring are most common in the most deprived areas. We also understand that caring itself can bring financial impacts, which is why there is a role for social security support.

We know that some people give up work or reduce their hours to care, with consequences both for carers’ financial wellbeing and their social isolation.

We understand that social isolation can be a particular risk for carers given the extra responsibilities they have and the financial burden often associated with caring. By engaging with carers in remote and island communities, we have heard how they face increased barriers such as higher living costs and greater distances to travel for caring or support.

4.2 **Our approach**

Continuing implementation of our commitments to reform carer benefits is one of two major priorities for carers policy. Increasing the income of carers through various approaches helps to address economic inequality as well as providing recognition of the invaluable contribution carers make to society.

Our vision highlights our aspiration for more carer friendly communities. We want our communities to be places where carers feel supported to look after family or friends. In a carer friendly community, public services might offer appointment times to fit around caring responsibilities; employers might offer flexible working conditions for staff; and universities and colleges might offer extensions or support to students who are also caring.

Carer friendly communities are places that reach out to support carers wherever they can by understanding caring, understanding disability and illness, and doing things differently.

In designing our newly devolved Social Security benefits, we have considered the needs of carers by drawing from their advice and lived-experience and will continue to do so with future developments and commitments.

Although employment law is reserved to the UK Government, we are using the levers at our disposal to raise awareness and encourage the implementation of fair work practices amongst employers to support carers in Scotland to access and balance work and caring where possible.

To address the risks of social isolation among carers, we are working in several ways to remove barriers to participation in training, education and employment opportunities as well as social and leisure activities. We are also implementing a
transport plan which focuses on improving door to door journeys for people with disabilities and removing the barriers which prevent them from accessing travel. For carers, this will assist in addressing social isolation of the people that they care for.

4.3 Social security – Carer’s Assistance
The Scotland Act 2016 gave the Scottish Government new powers relating to social security, and responsibility over certain benefits, including carer benefits. We are using these powers to create a Scottish social security system based on dignity, fairness and respect. In doing this, we are engaging with stakeholders and with people with experience of receiving benefits, to build a social security system that works for them. As part of this we are working with our Social Security Experience Panels – more than 2,400 volunteers from across Scotland with experience of the current benefits system – to shape how our benefits are designed and delivered.

We are using the opportunity provided by the devolution of carer benefits to improve support for carers, and ensure that social security is better aligned with wider carer services. We are working with carers and stakeholders to expand the support provided and to design benefits which better suit the needs of carers, so that they:

• are supported to look after their own health and wellbeing, improve their quality of life and reduce any negative impact of caring,
• participate fully in society and, if they choose, engage in training, education and employment opportunities, as well as social and leisure activities,
• have an increased sense of control and empowerment over their lives.

Currently the main social security benefit for carers is Carer’s Allowance (CA), an income-replacement benefit. CA is a payment of up to £66.15 per week for those who are caring for 35 or more hours a week for someone in receipt of specified disability benefits. CA is not means-tested but recipients cannot earn more than £123 per week after deductions, or be in full time education for more than 21 hours a week.

Only a small proportion of Scotland’s unpaid carers receive this support. In February 2019, there were 76,597 CA recipients in Scotland68. 69% of CA payments were made to female carers and 31% to male carers. CA recipients have increased in recent years and this is forecast to continue, as a result of increases in the State Pension age and the number of people receiving disability benefits, with an estimated 103,000 carers expected to be receiving CA by 2024/25.69

38% of those who are eligible for CA in Scotland do not receive it because they are also in receipt of another income replacement benefit such as State Pension, contribution based Jobseeker’s Allowance or Contributory Employment and Support Allowance which is paid at an equivalent or higher rate (this is known as the ‘overlapping benefit rule’). These carers are said to have an ‘underlying entitlement’ to CA and may be eligible for a premium or addition. This is extra money included in the calculation of means tested benefits such as Income Support and Pension

68 Carer’s Allowance at February 2019 and Carer’s Allowance Supplement, April 2019 eligibility date https://www2.gov.scot/Topics/Statistics/Browse/Social-Welfare/SocialSecurityforScotland/CASApr2019
Credit. People receiving Universal Credit (UC), who are also caring for 35 hours a week, may also qualify for extra money in their UC award – a Carer Element. These additional payments remain reserved to the UK Government.

We recognise that some people may be missing out on support because they don’t see themselves as ‘carers’, or because of wider barriers which prevent people from claiming benefits. We are committed to supporting people to receive what they are entitled to and are working with a range of partners who have experience in benefit take up to learn every lesson we can on what works best.

4.3.1 **Carer’s Allowance Supplement**

We considered it unfair that Carer’s Allowance was the lowest of all working age benefits. In recognition of the vital contribution carers make, increasing the support carers receive through CA was one of our first commitments using our new social security powers.

Our Carer’s Allowance Supplement (CAS) increases CA by 13% and these combined payments are now higher than Jobseeker’s Allowance for carers in Scotland. CAS is paid every six months to carers who are in receipt of a full or partial CA payment on the relevant qualifying date. Since launching in September 2018, 235,405 payments have been made to 91,550 carers who were eligible at any qualifying date. CA and CAS are uprated in line with inflation every year – in 2019/20, each CAS payment is £226.20.

CAS is paid to carers by the Scottish Government while CA continues to be paid by the Department for Work and Pensions (DWP) through an Agency Agreement. This is to allow us to provide additional support as soon as possible to some of the lowest income carers before we begin delivery of Scottish Carer’s Allowance from 2022 (see section 4.3.4).

4.3.2 **Young Carer Grant**

The Grant is a new annual payment for carers aged 16 to 18 (see section 5.6.1).

4.3.3 **Additional payment for carers of more than one disabled child**

It is estimated that there are 1,900 parents in receipt of Carer’s Allowance in Scotland who have caring responsibilities for more than one disabled child. Many parents of disabled children state that they receive less help and support than other carers as it is perceived that they are responsible for the child, regardless of the child having a disability. Furthermore, some parents with severely disabled children see their caring role as lifelong.

Currently carers can only receive one CA payment regardless of how many people they are caring for. The Scottish Government is committed to increasing CA for those looking after more than one disabled child within this parliamentary term. We

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71 https://contact.org.uk/media/381150/caringforsickanddisabledchildren2006appendix.pdf
are developing this policy by working with Social Security Experience Panels\textsuperscript{72} and members of the Carer Benefits Advisory Group (CBAG)\textsuperscript{73}.

4.3.4 Long term changes to Carer’s Allowance

We will open new applications for our replacement for Carer’s Allowance from early 2022. To begin with, new claims will be on broadly the same terms as the existing DWP benefit, and will entitle people to the other support we have made available to carers (CAS and the additional child payment).

However, there are other changes to eligibility that carers and stakeholders have asked us to consider. Due to complexities with other benefits, and our principle of protecting people and their payments, we will only make those changes when we are sure there will not be an adverse impact on carers in Scotland.

We will therefore consult in 2021 on the proposals we expect to make to support for carers in the longer term and respond to what carers tell us will support them when it is safe and practical to do so.

Throughout all of this work, carer support organisations and vitally, carers themselves, will continue to be central to designing both the overarching and the detailed policy that will deliver our vision for carers. The independent Disability and Carers Benefits Expert Advisory Group\textsuperscript{74} will also consider and make recommendations on longer term changes to carer benefits.

4.4 Carers and employment

4.4.1 Carers in the workforce

Around 270,000 people in Scotland combine work and unpaid care\textsuperscript{75}. This represents around 1 in 8 of the workforce. These numbers are likely to grow in the context of an aging population and more people living longer with complex conditions. Most people will be carers at some stage in their working lives.

Working age women are most likely to be carers and the likelihood of caring increases for those in their late 40s and early 50s. Over a quarter of women in this age bracket are carers. This represents a large and skilled portion of the workforce.

Balancing care with employment can be a tricky juggling act. Caring roles tend to change over time, with the intensity and impact of the role linked to changes in the life stages and health and wellbeing of the carer and the person they care for. Many carers give up work or reduce their hours in order to cope. This may be a free personal choice but can also feel like less of a choice when an unsupported carer reaches crisis point and feels that work is the element of their life that needs to ‘give’.

Giving up work can increase social isolation and loneliness for the carer and reduce financial security for them and their family. It can also have a longer term impact on

\textsuperscript{72} https://www.gov.scot/policies/social-security/engagement-on-social-security/
\textsuperscript{73} https://www.gov.scot/groups/carer-benefit-advisory-group/
\textsuperscript{74} https://www.gov.scot/groups/disability-carers-benefits-expert-advisory-group/
\textsuperscript{75} Scotland’s Carers report, Scottish Government, 2015: www.gov.scot/publications/scotlands-carers
their future career. When carers give up work, employers lose workers with valuable skills and experience and often incur high recruitment costs to replace lost workers.

Losing carers from an already shrinking workforce is a concern for the wider economy. It is estimated that that unpaid carers leaving employment cost the UK public purse £2.9 billion a year in welfare payments and lost tax revenue\(^76\). The impact of women reducing hours, not taking or applying for promotions, or leaving the labour market altogether in order to provide unpaid care, contributes towards Scotland’s gender pay gap.

Supporting carers to stay in or enter work therefore brings vital benefits to carers, employers and the economy. A range of Scottish Government policies aim to recognise and promote these benefits. Some of these are specific to carers. Many are part of the wider fair work agenda but will have particular importance for carers. Our aim is to support people into work by ensuring the employability offer in Scotland is person-centred, flexible and responsive to the needs of individuals and employers. We believe this is critical to help people access fair work and help them achieve their potential in an inclusive and fair economy.

The Fair Work Convention’s Fair Work Framework\(^77\) describes fair work as work that “offers all individuals an effective voice, opportunity, security, fulfilment and respect. Fair Work balances the rights and responsibilities of employers and workers, and generates benefits for individuals, organisations and society.”

Through our Fair Work agenda we are working to embed fair work within and across Scottish workplaces to achieve the aim for Scotland to be a world-leading Fair Work nation by 2025.

### 4.4.2 Policies to support carers to enter or re-enter employment

When caring roles end or change, carers can find it difficult to re-enter the workforce after long absences. Many of them can be older women. We support a range of work to support carers to return to work and to promote positive working practices which will encourage them to do so.

#### 4.4.2.1 Careers advice and guidance

Many of those who have been out of work for some time may require careers advice to help them consider their options. Careers advice and guidance is available from Skills Development Scotland\(^78\), with online services and offices across Scotland. For those who feel they will need additional support to get into work, Fair Start Scotland\(^79\) is available in every area and offers pre-work support for up to 18 months and in work support for up to 12 months.


\(^77\) https://www.fairworkconvention.scot/the-fair-work-framework/

\(^78\) Skills Development Scotland https://www.skillsdevelopmentscotland.co.uk/what-we-do/scotlands-careers-services/

\(^79\) Fair Start Scotland https://www.mygov.scot/help-find-job/
4.4.2.2 **Parental Employment support fund**
The Scottish Government will also shortly launch its Parental Employment Support Fund which will commence in November 2019. This aims to help reduce child poverty by providing tailored support to those parents who face considerable barriers returning to or progressing in work, with a particular focus on our priority families, including carers.

4.4.2.3 **Women returners**
We know that that many women struggle to return to work after a career break due to a lack of access to flexible working to support caring commitments. As a result they can find their job choices limited to lower paid, part time work and can experience pay inequality, underemployment, job insecurity, and a lack of opportunities for development and career progression. The Scottish Government announced that we will invest £5 million over the next 3 years to support around 2000 women returning to work following a career break. The programme is currently in development and information on progress will be available via this website\(^80\).

4.4.2.4 **Young carers and young adult carers**
Young people can find it difficult to transition from education to training and work while balancing an ongoing caring role. The following policies are intended to support them to make this shift:

- The 21 regional Developing the Young Workforce (DYW) groups connect employers with young people who are still at school and college. The groups’ role is to maximise the number of young people engaging in meaningful work experience and encourage employers to offer opportunities to young people facing additional barriers and to those who may need more flexibility.

- Following recommendations from the “Young Adult Carers and Modern Apprenticeships” report of August 2018, Skills Development Scotland actively promote Carer Positive practices, flexible working, best practice and support channels to Employers, Apprentices, Training Providers, Schools, Parents, Local Partners and internal staff. In line with these recommendations Modern Apprenticeships (MAs) are available on a flexible basis, with ultimate responsibility resting with the employer to enact this. Additionally for those still in school, undertaking a Foundation Apprenticeship whilst in the senior phase of school can give you a head start in completing your Modern Apprenticeship.”

4.4.2.5 **Policies which support carers to remain in employment**
Employers have the opportunity to play a unique role in promoting awareness and openness about caring roles. This can encourage people to identify themselves as carers and seek preventative support at an early stage, long before they reach crisis. Carer friendly policies, awareness and access to flexible working arrangements within an organisation can support carers to remain in work alongside a fluctuating caring role, benefitting both the employer and the carer.

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4.4.2.6 *Carer Positive employer accreditation scheme*

Carer Positive\(^81\) is an accreditation scheme that recognises those employers who put in place flexible and supportive working practices for people juggling work with unpaid care. It promotes the benefits for businesses, individual carers, society and the wider economy of supporting unpaid carers to remain in work alongside caring.

Carer Positive is free for employers of all sizes, across the public, private and third sectors. The requirements for accreditation are designed to be flexible and proportionate to the size and nature of the organisation involved. The scheme offers three levels of accreditation; *Engaged*, *Established* and *Exemplary*. These reflect the different stages an employer may be at on their journey to supporting carers in their workforce. Carer Positive is funded by Scottish Government and delivered on our behalf by Carers Scotland.

4.4.2.7 *Fair Work Action Plan*

Scotland’s Fair Work Action Plan\(^82\), published in February 2019, sets out the strategic approach the Scottish Government will take – working across government and with delivery partners and stakeholders to embed fair work as the norm in every Scottish workplace. Our approach is three-fold:

- supporting employers to adopt fair work practices;
- delivering Fair Work to a diverse and inclusive workforce; and
- embedding Fair Work across the Scottish Government.

The Action Plan recognises the challenges many carers face in sustaining a job and commits to promoting awareness and flexibility for unpaid carers in the workplace through Carer Positive.

4.4.2.8 *A Fairer Scotland for Women: Gender Pay Gap Action Plan*

Published in March 2019 the Plan\(^83\) aims to tackle the gender pay gap through a range of actions. One of the primary causes of the gender pay gap is unpaid care, which is still provided disproportionately by women. We know that flexible employment practices aimed at supporting carers who juggle work and caring responsibilities can play a large role in addressing gender inequality. A number of actions within the action plan are aimed at increasing the opportunities for well-paid flexible and part-time work, and towards improving employment practices to meet the needs of workers who are also carers:

- We are providing £159,000 from 2019-2020 to Family Friendly Working Scotland Partnership to support and promote the development of flexible and family friendly workplaces. The ‘Happy to Talk Flexible Working’\(^84\) strapline can be used by employers in their recruitment materials to ensure that carers know that the employer offers flexible working practices.

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\(^81\) [http://www.carerpositive.org/](http://www.carerpositive.org/)

\(^82\) [Fair Work Action Plan (2019)](https://economicactionplan.mygov.scot/fair-work/)


\(^84\) [Happy to Talk Flexible Working](https://www.familyfriendlyworkingscotland.org.uk/happy-to-talk-case/)
• The Scottish Government is funding a feasibility study for a ‘Centre for Flexible Work’ for Scotland. This Centre would explore new ways to increase the availability of quality, flexible work in Scotland.

• We are also providing £800,000 to the Workplace Equality Fund, which supports employers to deliver innovative solutions to overcome workforce inequalities, including pay gaps and to encourage employers to embed Fair Work practices within their workplaces.

• We will also fund the Women Returners Programme mentioned above.

4.5 Social isolation and loneliness

There are groups in society that go above and beyond what is expected, sometimes at the expense of their own immediate needs and wellbeing. Scotland’s carers deserve to be able to live a full life, which includes time for socially connecting. Research from Carers UK suggests that “8 out of 10 carers have felt lonely or socially isolated as a result of looking after a loved one”. That is why another key part of our work is driving progress to combat social isolation and loneliness. Recently we launched “A Connected Scotland”, our national strategy for tackling these issues and building social connections85

The Government has an important role in tackling these issues, and we will be working to create the conditions for change and take a cross-governmental approach. A Ministerial Steering Group, chaired by the Minister for Older People and Equalities, will drive Scottish Government cross portfolio work and oversight of the strategy.

We have also established a National Implementation Group, also chaired by the Minister for Older People and Equalities which comprises key organisations with a role in driving progress to embed a cross-sectoral approach through the development and implementation of a shared delivery plan for the strategy. To support the successful implementation of the strategy, we’re committing up to £1 million of investment over the next two years to help build our collective capacity and to pilot innovative approaches.

4.6 Transport

Our National Transport Strategy86 sets our ambitions and priorities for Scotland’s transport system over the next 20 years. The vision is that We will have a sustainable, inclusive and accessible transport system helping to deliver a healthier, more prosperous and fairer Scotland for communities, business and visitors.

The strategy’s equality priority recognises transport plays an important role in delivering a fully inclusive society in which disabled people have the right to equal access within their communities. However, barriers to travel can create considerable

problems for people with disabilities and their carers who often accompany them on public transport.

The Going Further - Scotland’s Accessible Travel Framework\(^{87}\) ten year plan focuses on improving the door to door journeys for people with disabilities and removing the barriers which prevent them from accessing travel. For carers, this will assist in addressing social isolation of the people that they care for.

The overarching aim of the Framework is that disabled people in Scotland can travel with the same freedom, choice, dignity and opportunity as other citizens. The first Delivery Plan\(^ {88}\) was published in June 2019. The Scottish Government is committed to over £1 billion of investment in public, and sustainable transport options. Progress so far includes:

- investment of £202.1 million in 2018-19 in the National Concessionary Travel scheme\(^ {89}\) which offers free bus travel to elderly and disabled people through the National Entitlement Card.
- a commitment to extend the National Concessionary Travel Scheme to provide companion cards for eligible disabled children under age 5. This will provide the benefits of free bus travel to about 3,000 families and carers each year.
- a commitment to introduce free bus travel for recipients of the Young Carer Grant during financial year 2020/21. (see also section 5.6.5).

\(^{87}\) Going Further- Scotland’s Accessible Travel Framework

\(^{88}\) Scotland’s Accessible Transport Framework Delivery Plan 2019-20

\(^{89}\) https://www.transport.gov.scot/concessionary-travel/
5. **Young Carers**

**Strategic Outcome**
Young carers are supported; and protected from inappropriate caring and negative impacts on their education, social lives and future development.

### 5.1 Why this is important

There are an estimated 31,000 young carers in Scotland under the age of 18. Young carers often go above and beyond what is expected of them as young people.

We know that 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 mature, valuable skills and values and a sense of pride and increased self-esteem from their role\(^90\).

However where young carers undertake inappropriate caring responsibilities or care for long hours, this can have a detrimental effect on their wellbeing. It could also negatively impact on their educational attainment, relationships with their peer group and affect their mental health.

It is recognised that young carers often find it challenging to identify 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\(^91\). There can also be stigma associated with a younger person undertaking a caring role. Sometimes families or young people will have concerns about potential negative repercussions of social work intervention\(^92\), leading to young carers actively avoiding seeking help or support. A lack of awareness or support for their caring role can therefore lead to young people feeling lonely and isolated. As a consequence of all of this, there are many young carers who do not identify, either through a lack of awareness, or through choice.

Research also shows that young carers feel that their experiences and knowledge in relation to the cared-for person are often overlooked by professionals\(^93\) leaving them feeling excluded and undermined.

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 and open to most young people can be restricted for young carers due to the additional responsibilities and pressures that come with caring.

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\(^{90}\) Becker, 2007  
\(^{92}\) Moore and McArthur, 2007  
\(^{93}\) McAndrew, Warne, Fallon and Moran, 2012
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. Young carers also report experiences of social isolation.

5.2 Our approach

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 carer voice and engagement, health and social care and financial and social inclusion.

The principles and values embedded in the Getting it right for every child (GIRFEC) approach apply for young carers. Getting it right for every child is Scotland's approach to promoting and improving the wellbeing of every child, including those who hold a caring role.

This approach is based on children's rights, taking their development, decisions made in their best interests and respect for their views into consideration. The GIRFEC principles reflect the United Nations Convention on the Rights of the Child (UNCRC).

GIRFEC is central to all government policies which support children, young people and their families and is delivered by encouraging service providers, third sector organisations and public bodies to work in collaboration with children, young people and their families. This will allow children and young people to achieve their full potential across all of the SHANARRI wellbeing indicators, helping them to thrive and be able to better respond to the challenges and opportunities that life brings. GIRFEC also respects parents' rights under the European Convention on Human Rights (ECHR).

In April 2018, the Carers (Scotland) Act established new rights for young carers, including a right to a young carer statement which will identify any personal outcomes that are important to them and their needs for support. The Act also introduces new rights for young carers to be involved in conversations and decision-making about any support provided to the cared-for person, including when they are being discharged from hospital. We are clear that, for our young people, caring should not be a barrier to education, social and leisure opportunities, or accessing education or employment.

Schools play a key role in identifying and supporting many young carers and the rights under the Act are intended to work alongside provisions about additional support for learning as well as the GIRFEC approach.

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94 Scotland’s Census, 2011
95 Carers Trust, Protecting the Health and Wellbeing of Young Carers
96 GIRFEC https://www.gov.scot/policies/girfec/
97 UNCRC https://www.cypcs.org.uk/rights/uncrcarticles
99 ECHR https://www.echr.coe.int/Documents/Convention_ENG.pdf
5.3 Young carer voice and engagement

5.3.1 Scottish Young Carers Festival
The Scottish Young Carers Festival\textsuperscript{100} is an annual event that has taken place since 2008. It is funded by the Scottish Government and delivered on our behalf by Carers Trust Scotland and the Scottish Young Carers Services Alliance.

As well as enabling young carers from across Scotland to take a break from caring and enjoy leisure activities with their peers, the Festival gives young carers an opportunity to have their voices heard by talking to local and national decision makers about what matters to them and providing feedback for national consultations. In recent years, this has helped bring some key young carer issues to the fore and played a role in influencing national and local policy development.

Young carers are usually able to attend the Festival in a group from their local young carers service.

5.3.2 Young Carer Panel
The Young Carer Panel\textsuperscript{101} is an invaluable aspect of the social security Experience Panels discussed in section 2.3.5. The views of over 50 young adults with experience of regular care are represented in the Panel. The group have shared the impact of their caring responsibilities and helped shape specific aspects of the new Young Carer Grant.

5.4 Health and social care

5.4.1 Carers Act for young carers
The Carers Act introduces many of the same rights for young carers as it does for adult carers. Young carers have a right to a young carer statement to help identify their needs for support and personal outcomes. For more information on this, please see Chapter 2 on Health and Social Care Support.

Funded by the Scottish Government, Carers Trust Scotland and the Scottish Young Carers Services Alliance have produced a Young Carers Jargon Buster\textsuperscript{102} which aims to help explain some of the more difficult terminology in the Act, for young carers.

To assist with the transition from young carer to adult carer, the Carers Act makes provision for a young carer statement, and any support that comes from it, to be maintained until the preparation of an adult carer support plan.

5.4.2 Keeping young carers safe from harm
It is important to ensure that young carers are enabled to be children and young people are first and foremost and relieved of any inappropriate roles to allow them to have a quality of life. For some children and young people in certain situations a

\textsuperscript{100} Scottish Young Carers Festival https://carers.org/scottish-young-carers-festival
\textsuperscript{101} Young Carer Panel https://www.gov.scot/publications/social-security-young-carer-panel-youve-told-far-research-findings/
\textsuperscript{102} Young Carers Jargon Buster https://carers.org/sites/default/files/media/carers_scotland_act_2016_jargon_buster_for_young_carers.pdf
response to risk of harm may be required without delay following the local multi-agency child protection\(^{103}\) guidelines.

### 5.5 Support in schools

Schools play a unique role in identifying and supporting young carers. With GIRFEC, education staff have a responsibility to support the wellbeing of every child. They need to take into consideration any wider influences on the child or young person when thinking about their wellbeing, so that the right support can be offered. This includes the impact of caring on a child or young person.

We know that young carers often report feeling isolated, stigmatised, bullied and unsupported in schools\(^{104}\) due to their caring role and that caring can lead to increased absenteeism or lateness.

However, research also shows that young carers are more likely to enjoy their time spent at school than the general school population\(^{105}\). This may be because they see this time as an opportunity to engage with friends and as time away from caring.

#### 5.5.1 Additional Support for Learning

It may be that young carers will require some additional support to enable them to make the most of their learning and to reach their full potential. This can be long or short term depending on need. Education authorities have duties\(^{106}\) to identify, provide for and review the additional support needs of all their pupils. This includes ensuring that there are the staff and resources in place to support pupils in their learning.

The latest amendments to the legislation mean that children who are aged 12 to 15 will be able to ask for their additional support needs to be identified and planned for and be part of discussions about the support they will receive.

The service My Rights, My Say\(^{107}\) supports children and young people to help them secure the use of their own rights under additional support for learning legislation.

### 5.6 Social and financial inclusion

#### 5.6.1 Young Carer Grant

We will launch our new Young Carer Grant for those young carers aged 16 to 18, with significant caring responsibilities. The Grant is a £300 annual payment for carers aged 16 to 18 and will be available in autumn 2019.

It is intended that the Grant helps young carers to:

- look after their own health and wellbeing, improve their quality of life and reduce any negative impact of caring

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\(^{104}\) Protecting Young Carers from Bullying, Carers Trust, 2016; Scottish Young Carers Festival Report, Carers Trust, 2018; Sempik and Becker, 2010.

\(^{105}\) [https://www.cypcs.org.uk/ufiles/CopingWithCaring.pdf](https://www.cypcs.org.uk/ufiles/CopingWithCaring.pdf)

\(^{106}\) Education (Additional Support for Learning) (Scotland) Act 2004 (as amended)

\(^{107}\) My Rights, My Say [https://enquire.org.uk/myrightsmysay/](https://enquire.org.uk/myrightsmysay/)
• participate fully in society and, if they choose, engage in training, education and employment opportunities, as well as social and leisure
• have an increased sense of control and empowerment over their lives.

The grant will be available to young carers who provide care to a person(s) normally paid a qualifying disability benefit, care for 16 hours a week and to those who do not qualify for Carer’s Allowance. Young carers will be able to combine the number of hours spent providing care for up to three people in order to meet the 16 hours eligibility criteria.

5.6.2 **Education Maintenance Allowance (EMA)**

EMA is available in Scotland to eligible people aged 16 to 19 who have reached school leaving age.

Scottish Funding Council guidance\(^{108}\) encourages local authorities and colleges to promote the uptake of EMA to young carers. The guidance also highlights that a degree of flexibility around attendance patterns should be afforded to young carers when administering EMA. To enable this to happen, young carers should highlight their caring responsibility on the EMA application form. A conversation to agree on a suitable flexible attendance pattern should take place with the school or college, and then written into the student’s Learning Agreement.

5.6.3 **Transitions from school to higher and further education**

Young adult carers, between around ages 16 to 25, face particular pressures as they may be leaving school, and transitioning into college or university. At this key stage, it can also be especially hard to juggle this change with the demands and responsibilities of their caring role.

5.6.3.1 **Support from Education Authorities**

Education authorities have specific duties\(^{109}\) to prepare pupils with additional support needs for their post-school transition, which should happen no later than 2 years before they leave school.

Young people with additional support needs should engage personally in the transition planning process. Whatever prospective school leavers require to learn in order to make the transition successful should, in good practice, be planned carefully and in a timely manner.

5.6.3.2 **Student Awards Agency Scotland (SAAS) funding support**

SAAS has worked closely with key stakeholders, including the Scottish Youth Parliament, Carers Trust Scotland and student carers, to better understand the needs of student carers and raise awareness of higher education student support.

SAAS has engaged with student carers to gather feedback on our literature and aspects of our online application that are relevant to this cohort to ensure they understand the support available to them and how to access this support. Some of

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\(^{109}\) Education (Additional Support for Learning) (Scotland) Act 2004 (as amended)
the support available to student carers includes the dependent’s grant. This is an income-assessed grant that SAAS may pay out to student carers who meet the criteria.

5.6.3.3 University and college support for student carers
There are two award schemes which promote better support for student carers, one is aimed at further education colleges and the other at universities. The ‘Going Further for Student Carers Recognition Award’ scheme assists and encourages further education colleges to develop their policies and practices to improve support for student carers.

The ‘Going Higher for Student Carers Recognition Award’ provides a framework for universities to ensure they are identifying and supporting student carers. This helps them to develop their policies and practices to improve support for student carers at university.

Both schemes have been developed by Carers Trust Scotland, supported by the Scottish Funding Council who are funded by the Scottish Government. The Going Further for Student Carers Recognition Award is also supported by the College Development Network.

5.6.4 Support into employment
Please see Chapter 4 on Social and Financial Inclusion for more information on this.

5.6.5 Free bus travel for recipients of the Young Carer Grant
We have committed to introduce free bus travel for recipients of the Young Carer Grant during financial year 2020-21.

5.6.6 Young Scot card extra discounts and opportunities
Young Scot has launched a new and exclusive package of discounts and opportunities for young carers with a Young Scot card across Scotland to access and enjoy.

Co-created with a young carer “vision panel”, the development of the new package has been fully informed by young carers and is fully funded by the Scottish Government. A simple application is required through the Young Scot website which also contains further information about what’s on offer.

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110 Going Further for Student Carers https://carers.org/going-further-scotland
111 Going Higher for Student Carers https://carers.org/going-higher
ANNEX: Consultation on Draft Carers Strategic Policy Statement

Executive Summary

The Carers Strategic Policy Statement is intended to assist local and national strategic planning and policy development in the statutory, independent and third sector to understand the existing national policies and approaches in place to support unpaid carers in Scotland. By having this “map” of national carer support policies and strategies, those who have a role in commissioning or the provision of support for carers can make fully informed decisions about different approaches and models, and tap into existing opportunities.

The draft puts the individual carer in the centre and focuses on national policies to address four different aspects of carer support:

- Carer Voice and Engagement
- Health and Social Care Support
- Social and Financial Inclusion
- Young Carers

Why we are consulting?

The Carers Strategic Policy Statement is intended to maximise the benefits from national policies and approaches intended to support carers (including major ongoing reforms such as implementation of the Carers (Scotland) Act and the development of our new social security powers for carers). It aims to do this by connecting a wide range of existing policies.

The draft Statement has been developed following intensive informal engagement with stakeholders. We want to ensure it covers the right information and is presented in a way which will be genuinely useful to its intended audience. We are consulting formally on the draft document to test that it achieves these aims.

The responses to the consultation will be analysed and the results will be used to help ensure the Carers Strategic Policy Statement covers the right information and is presented in a way which will be genuinely useful to its intended audience.

This consultation is open for a period of 12 weeks. (30/09/2019 – 13/12/2019)

We invite your views to each of the questions below.
Consultation on Draft Carers Strategic Policy Statement
Overall document

Question 1
The Carers Strategic Policy Statement aims to map the main policies across the Scottish Government which are relevant to carers; and set out the overall approach and outcomes these policies contribute towards. Do you agree that the draft achieves this?

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Please provide reasons for your response.

Question 2
The Carers Strategic Policy Statement is intended to inform strategic planning and policy development for local and national organisations working with carers. If you represent such an organisation, does the draft provide valuable information for that purpose?

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree
- Don’t represent an organisation working with carers

Please provide reasons for your response.
Consultation on Draft Carers Strategic Policy Statement
Chapter 1 – Introduction

Question 3
Do you agree with the vision and principles as proposed in the strategic framework?

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Please provide reasons for your response.

Chapter 2 - Carer Voice and Engagement

Question 4
Do you agree with the proposed strategic outcome:

“Carers voices are heard and their views and experiences are taken into account in decisions which affect them?”

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Please provide reasons for your response.

Question 5
We want this document to be helpful and concise. Do you agree that this chapter provides enough information about the most important issues about carer voice and engagement?

- Too much information
- About right
- Not enough information

Please explain your answer if you have suggestions for improvements.
Question 6
The proposed strategic outcome is one of the “National Health and Wellbeing Outcomes” set in legislation to guide the integration of health and social care:

“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?”

Do you agree with our proposed approach of using the same outcome for this document?

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Please provide reasons for your response.

Question 7
We want this document to be helpful and concise. Do you agree that this chapter provides enough information about the most important issues on health and social care support for carers?

- Too much information
- About right
- Not enough information

Please explain your answer if you have suggestions for improvements.
Question 8
Do you agree with the proposed strategic outcomes:

“Carers access the financial support and assistance they are entitled to?”

“Carers are able to take up or maintain meaningful employment alongside caring?”

“Carers can participate in and are valued by their community and wider society?”

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Please provide reasons for your response.

Question 9
We want this document to be helpful and concise. Do you agree that this chapter provides enough information about the most important issues on social and financial inclusion for carers?

- Too much information
- About right
- Not enough information

Please explain your answer if you have suggestions for improvements.
Consultation on Draft Carers Strategic Policy Statement  
Chapter 5- Young carers

Question 10

Do you agree with the proposed strategic outcome:

“Young carers are supported; and protected from inappropriate caring and negative impacts on their education, social lives and future development?”

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Please provide reasons for your response.

Question 11

We want this document to be helpful and concise. Do you agree that this chapter provides enough information about the most important issues for young carers?

- Too much information
- About right
- Not enough information

Please explain your answer if you have suggestions for improvements.
RESPONDING TO THIS CONSULTATION

We are inviting responses to this consultation by **13/12/2019**.

Please respond to this consultation using the Scottish Government’s consultation hub, Citizen Space (http://consult.gov.scot). Access and respond to this consultation online at https://consult.gov.scot/health-and-social-care/carers-strategic-policy-statement/

You can save and return to your responses while the consultation is still open. Please ensure that consultation responses are submitted before the closing date of 13/12/2019.

Alternatively, you can e-mail your response and the completed Respondent Information Form, which is also available separately on the Scottish Government website (see “Handling your Response” below) to: carerspolicy@gov.scot

If you are unable to respond online, please complete the Respondent Information Form (see “Handling your Response” below) and send it to:

Consultation on Draft Carers Strategic Policy Statement
Carers Policy Branch
Scottish Government
St Andrew’s House, GE.15
Regent Road
Edinburgh
EH1 3DG

Handling your response

If you respond using the consultation hub, you will be directed to the About You page before submitting your response. Please indicate how you wish your response to be handled and, in particular, whether you are content for your response to be published. If you ask for your response not to be published, we will regard it as confidential, and we will treat it accordingly.

All respondents should be aware that the Scottish Government is subject to the provisions of the Freedom of Information (Scotland) Act 2002 and would therefore have to consider any request made to it under the Act for information relating to responses made to this consultation exercise.

If you are unable to respond via Citizen Space, please complete and return the Respondent Information Form included in this document.

To find out how we handle your personal data, please see our privacy policy: https://beta.gov.scot/privacy/
Next steps in the process

Where respondents have given permission for their response to be made public, and after we have checked that they contain no potentially defamatory material, responses will be made available to the public at http://consult.gov.scot. If you use the consultation hub to respond, you will receive a copy of your response via email.

Following the closing date, all responses will be analysed and considered along with any other available evidence to help us. Responses will be published where we have been given permission to do so. An analysis report will also be made available.

Comments and complaints

If you have any comments about how this consultation exercise has been conducted, please send them to the contact address above or to : carerspolicy@gov.scot

Scottish Government consultation process

Consultation is an essential part of the policy-making process. It gives us the opportunity to consider your opinion and expertise on a proposed area of work.

You can find all our consultations online: http://consult.gov.scot . Each consultation details the issues under consideration, as well as a way for you to give us your views, either online, by email or by post.

Responses will be analysed and used as part of the decision making process, along with a range of other available information and evidence. We will publish a report of this analysis for every consultation. Depending on the nature of the consultation exercise the responses received may:

- indicate the need for policy development or review
- inform the development of a particular policy
- help decisions to be made between alternative policy proposals
- be used to finalise legislation before it is implemented

While details of particular circumstances described in a response to a consultation exercise may usefully inform the policy process, consultation exercises cannot address individual concerns and comments, which should be directed to the relevant public body.
Consultation on Draft Carers Strategic Policy Statement

RESPONDENT INFORMATION FORM

Please Note this form must be completed and returned with your response.

To find out how we handle your personal data, please see our privacy policy: https://beta.gov.scot/privacy/

Are you responding as an individual or an organisation?

☐ Individual
☐ Organisation

Full name or organisation’s name

Phone number

Address

Postcode

Email

The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:

☐ Publish response with name
☐ Publish response only (without name)
☐ Do not publish response

Information for organisations:
The option ‘Publish response only (without name)’ is available for individual respondents only. If this option is selected, the organisation name will still be published.

If you choose the option ‘Do not publish response’, your organisation name may still be listed as having responded to the consultation in, for example, the analysis report.
We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

☐ Yes
☐ No