# Report

#### **Carers Strategy**

### **Edinburgh Integration Joint Board**

29 March 2019



- The <u>Carers (Scotland) Act 2016</u> is designed to support carers' health and wellbeing and help make caring more sustainable. Duties from 1 April 2018 include:
  - a) a duty for local authorities to provide support to carers, based on the carer's identified needs which meet the local eligibility criteria
  - b) a specific adult carer support plan (ACSP) and young carer (YCS) statement to identify carers' needs and personal outcomes
  - a requirement for local authorities to have an information and advice service for carers which provides information and advice on, amongst other things, emergency and future care planning, advocacy, income maximisation and carers' rights
  - d) to produce a Carers Strategy that outlines local priorities for the implementation of the act
- 2. The key provisions are summarised here and in the Scottish Government's Carers' charter, setting out carers' rights under the Act.
- 3. The Edinburgh Carers Strategy 2019-2022 outlines the Edinburgh Health and Social Care Partnership's (EHSCP) current position, vision, priorities and implementation to meet the new duties of the act for young and adult carers throughout Edinburgh and was developed in partnership with the third sector and unpaid carers.
- 4. The Carers Strategy 2019-22 takes account of the learning from the independent review carried out by Edinburgh Voluntary Organisations Council (EVOC) of the previous Edinburgh Joint Carers Strategy 2014-2017 as well as information from citywide consultations. Outcomes from the current pilots will also form the detail of an implementation plan.







#### Recommendations

- 5. The Integration Joint Board is asked to:
  - i. Approve progress being made on the development of the strategy and implementation plan, which is being produced with third sector stakeholders, internal partners and led by the lead officer for carers.
  - ii. Agree that the six priorities identified will meet the outcomes of the Carer Strategy.

#### **Background**

- 6. The previous Edinburgh Joint Carer Strategy 2014-2017 was reviewed independently by Edinburgh Voluntary Organisations Council (EVOC) in 2017 to measure the impact of the Joint Carers Strategy. The review made six recommendations for the new Edinburgh Joint Carer Strategy:
  - a) Focus on Implementation
  - b) Broaden ownership of the strategy
  - c) Maintain the same priorities in the new strategy
  - d) Recognise the fundamental differences of young carers
  - e) Futureproof the strategy
  - f) Measure Impact
- 7. The Carers (Scotland) Act 2016 is designed to support carers' health and wellbeing and makes provision for enhanced carers' rights for support in the caring role including:
  - a) early identification of carers' needs for support
  - b) carers' entitlement to adult carer support plans and young carer statements
  - c) the provision of support to carers
  - d) the enabling of carer involvement in certain services;
  - e) the preparation of local carer strategies and the
  - f) establishment of information and advice services for carers

8. This strategy has been developed in partnership with EHSCP, key stakeholder partners from the third sector, young and adult carers and incorporates the six recommendations and the new duties from the act.

#### **Main report**

- 9. Scottish Government census figures state there is 65,084 carers in Edinburgh, or 13.7% of the population. EHSCP and joint planning partners recognise carers as an equal partner in care, and support the principles developed in partnership with carers and other stakeholders by Equal Partners in Care (EPiC)<sup>1</sup>.
- 10. The EPiC principles are:
  - a) Carers are identified
  - b) Carers are supported and empowered to manage their caring role
  - c) Carers are enabled to have a life outside of caring
  - d) Carers are fully engaged in the planning and shaping of services
  - e) Carers are free from disadvantage or discrimination relating to their role
  - f) Carers are recognised and valued as equal partners in care
- 11. The EHSCP will identify carers as soon as possible within their caring role (preferably at point of diagnosis), signpost them to services for information and advice. Where further support is required, the EHSCP will work to identify any specific, unmet, assessed needs through completing an ACSP to support carer health and wellbeing.
- 12. Demand for services will continue to increase with Edinburgh's population predicted to grow by 19% to 505,363 between 2013 and 2033. Recent estimates indicate one in ten adults are an unpaid carer and this will have a serious impact on both carers and any services provided for them in the years to come.
- 13. Unpaid carers will have a key role in achieving the strategic objective of shifting the balance of care. It is essential for sufficient, flexible support to be available allowing carers to carry out their caring role while maintaining their wellbeing, especially those carers with a greater risk of poorer health. Identifying carers early and providing support they identify as being missing, for example swimming lessons or purchasing technology, which meets individual carer needs, improves outcomes whilst reducing costs.

<sup>&</sup>lt;sup>1</sup> EPiC was a joint project between NHS Education Scotland and the Scottish Social Services Council aimed at achieving better outcomes for all involved in the caring relationship.

- 14. EHSCP and Communities and Families will focus on working with young and adult carers, developing services that increase personalisation and choice, within the communities in which they live, to improve individual outcomes.
- 15. EHSCP will support carers as early as possible in order to tackle health inequalities, working holistically, developing preventative interventions to meet carers needs. Focusing on having a good conversation to reduce the risk of over providing support, improving responses, address the piece(s) of support that is missing to meet individual needs.
- 16. To ensure effective implementation of the strategy; future reviews and the ongoing development of services including monitoring of the strategy is currently being developed with all partners.
- 17. Partners and the local authority are required to report carer census data to the Scottish Government on an annual basis, evidencing outcomes and the impact of the implementation of act. Key performance indicators (KPI's) and outcomes will assist in planning for future services as trends, demands and gaps emerge through the analysis of the data. This coupled with measuring outcomes and impact, partners surveys, feedback data and ongoing consultations with carers will inform all future developments.
- 18. An implementation plan will be developed around the six priorities listed in table 1. The implementation plan will provide details on specific tasks, who owns those tasks, key milestones, their completion and review date.

Table 1.	High level priorities and activities	
Priority	Activities	
1.Identifying Carers	<ul> <li>Point of Diagnosis pathways</li> <li>Awareness raising and publicity for employers and workforce</li> <li>Complete Adult Carer Support Plans and Young Carer Statements</li> </ul>	
2. Information and Advice	<ul> <li>Access to services using technology</li> <li>Accessible carer training</li> <li>Welfare benefits advice</li> <li>Self-directed support and other carer grants</li> <li>Advocacy</li> </ul>	
3. Carer Health and Wellbeing	<ul> <li>Carer support that offers a range of responses</li> <li>Emotional support and/or counselling</li> <li>Emergency planning</li> <li>Services available all year</li> <li>Transitions planned and supported. Carer stress reduced. Carers supported to make future plans (Power of Attorney/guardianship), support with,</li> </ul>	

	anticipatory care planning, preventative services,
	culturally appropriate services
4. Short Breaks	<ul> <li>Development and implementation of a Short</li> </ul>
4. Short breaks	Breaks Statement.
	<ul> <li>Flexible, responsive and creative short breaks</li> </ul>
	Management of short breaks funding
	<ul> <li>Respitality and breaks with Third sector</li> </ul>
5. Young Carers	<ul> <li>Identifying young carers as soon as possible</li> </ul>
o. roung ourors	<ul> <li>Identifying and improving transition periods for</li> </ul>
	young carers
	<ul> <li>Work with higher education establishments to</li> </ul>
	develop joint plans/strategies
	<ul> <li>Work with schools in their clusters for joint plans</li> </ul>
	within localities
	<ul> <li>Employment and training support.</li> </ul>
6. Personalising support for	<ul> <li>Completing ACSP/YCS as soon as possible with</li> </ul>
Carers	carers
	<ul> <li>Signposting to existing services</li> </ul>
	<ul> <li>Personalised solutions to carers</li> </ul>
	<ul> <li>Supporting carers own solutions</li> </ul>
	Use self-directed support options
	Carers offered more choice and control to
	support their unmet needs
	Getting It Right for Every Child/Getting it Right for
	Everyone framework used
	Use of technology enabled care
	Digital inclusion
	Personalised data stores for carer information to
	reduce the number of times carers have to tell
	their and the cared for's "story" and share
	relevant information

#### **Key risks**

- 19. It is anticipated that demand for services and support will increase as more carers are identified. There is a risk if services are not redesigned the needs of carers cannot be met. Doing more of the same is no longer viable and the pilots have shown the new ways of working do work.
- 20. The budget provided needs to be available to support the shift in the balance of care and continued finance pressures may present a risk as budgets are reduced.

#### **Financial implications**

21. More work is required to develop services and resources that will meet both young and adult carers needs. The implementation of the Carers (Scotland) Act 2016 is supported by a five-year financial settlement (Edinburgh's percentage is shown in Table 2.). A detailed implementation plan will be produced if the 6 key priorities are agreed in this report. The high-level priorities and actions are outlined in table 1.

Edinburgh Allocation	2018/19	2019/20	2020/21	2021/22	2022/23
Provision of ACSPs	£153,000.00	£482,368.00	£702,160.00	£1,362,374.00	£1,582,165.00
Provision of YCSs	£18,000.00	£36,073.00	£67,112.00	£97,312.00	£128,352.00
Information and Advice	£277,000.00	£255,026.00	£255,026.00	£255,026.00	£255,026.00
Duty to Support adult Carers	£312,000.00	£833,447.00	£1,432,757.00	£3,044,200.00	£4,296,678.00
Duty to Support young Carers	£61,000.00	£122,898.00	£245,798.00	£368,697.00	£544,698.00
Additional Short Breaks Support	£198,000.00	£197,980.00	£197,980.00	£197,980.00	£197,980.00
CIS	£420,000.00	£419,702.00	£419,702.00	£419,786.00	£419,869.00
Local Carer Strategies	£27,000.00	£0.00	£0.00	£13,424.00	£0.00
TOTAL	£1,466,000.00	£2,347,494.00	£3,813,494.00	£5,758,799.00	£7,424,768.00

(Table2. Estimated Five Year Scottish Government Settlement)

- 22. There will be an effective co-production approach to developing new specifications to support young and adult carers for as long as they need that support. Gaps in provision and service visibility within some localities will be address with new contracts in place for 1 April 2020.
- 23. The implementation and rolling out of the findings North-West pilot which reflects a change in allocating funds to unpaid carers that reduced the pathway from 18 months to ten working days.
- 24. Work is also ongoing to upskill staff to new ways of working so that staff can feel confident that when the Adult Carer Support Plan has been completed and if a budget to purchase, for example swimming lessons, night classes etc, they can allocate that money within the agreed governance structure.
- 25. The information within Table 2. Show the actual and estimated annual settlement from the Scottish Government, it is worth noting however, the Carer Information Strategy (CIS) money is monies previously available and managed by NHS Lothian but included as part of the settlement and sits with the EIJB.

26. There ongoing work nationally to quantify the true impact of the carers act, no provision was made for replacement care and the figures in the financial memorandum were strongly challenged by SWS at the time.

#### **Implications for Directions**

27. There are no Directions required as an immediate result of this paper.

#### **Equalities implications**

28. An Integrated Impact Assessment has been completed for the implementation of the Act.

#### **Sustainability implications**

29. The strategy supports a shift towards supporting and enabling carers which would be anticipated to have a positive impact on the sustainability of their caring role.

#### **Involving people**

- 30. Unpaid carers are involved at all levels of governance in respect of the implementation of the Carers (Scotland) Act 2016 including the two unpaid carer members who are members of the Edinburgh Integration Joint Board.
- 31. Carers' organisations working with both adult and young carers also sit on the Strategic Carers' Partnership that oversees the work of all workstreams. There has been consultation with both adult and young carers throughout the development of the eligibility criteria, the adult carers' support plan and young carer's statement and their input has influenced and changed the drafts to date. This engagement will be ongoing throughout the development and implementation of the Carers (Scotland) Act 2016.
- 32. EHSCP are currently working with the Young Carers' Forum to identify older young carers (over 18) who can attend the Strategic Carers' Partnership group to help with ongoing developments.
- 33. Carers have been widely consulted regarding the review of the Edinburgh Joint Carers Strategy 2014-2017, during the reviews of services and identifying priorities for the Scottish Government settlement. These consultations have used online surveys, paper surveys with follow-up face to face meetings and discussions to clarify understanding with both unpaid carers and professionals.

#### Impact on plans of other parties

34. The work with unpaid carers impacts on all areas of the Health and social Care Partnership as a cross cutting theme.

#### **Background reading/references**

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#### **Appendices**

**Appendix 1** Draft Edinburgh Joint Carers Strategy

# Edinburgh Joint CARERS' STRATEGY

for children, young people and adults who give unpaid care to others





Working together for a caring, healthier, safer Edinburgh

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Joint Carers Strategy?

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## No carer should be disadvantaged by undertaking a caring role.

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 well-being. (Scottish Government)

### **Executive Summary**

The <u>Carers (Scotland) Act 2016</u> is designed to support carers' health and wellbeing and help make caring more sustainable. New duties for local authorities from 1 April, 2018 include:

• a duty for local authorities to provide support to carers, based on the carer's identified needs which meet the local eligibility criteria.

- a specific adult carer support plan and young carer statement to identify carers' needs and personal outcomes.
- a requirement for local authorities to have an information and advice service for carers which provides information and advice on, amongst other things, emergency and future care planning, advocacy, income maximisation and carers' rights.

The key provisions are summarised here and in The Scottish Government's <u>Carers'</u> <u>charter</u>, setting out carers' rights under the Act.

The Act contributes to the Scottish Government's vision of a healthier and fairer Scotland, and sits alongside related policy on the integration of Health and Social Care, new social security powers; and the Fair Work agenda.

The Edinburgh Carers Strategy 2019-2022 outlines Edinburgh's current position, vision, priorities and implementation to meet the new duties of the act for young and adult carers throughout Edinburgh developed in partnership with the third sector and unpaid carer

#### Introduction

The Edinburgh Health and Social Care Partnership (EHSCP) recognise the crucial role young and adult carers contribute to their communities across Edinburgh.

Edinburgh City Health & Social Care Partnership has adopted the following as a working definition of a carer:

"A Carer is 'A person of any age who provides, or intends to provide, unpaid help and support to a relative, friend or neighbour who cannot manage to live independently without the Carer's help due to frailty, illness, disability or addiction'." (Scottish Government 2016)

A Young Carer is a Carer who is under 18 years old or is 18 years old and is still at school. A Young Carer is more than just a Young person who provides unpaid care. They are Children and Young People first, with rights to live a full life and not miss out on childhood.

A Young Adult Carer is aged 16 to 29 who cares, unpaid, for a family member or friend with an illness, or disability, mental health condition or an addiction. Young Adult Carers are usually aged from 18 to 25."

#### Number of carers in Edinburgh:

Since the publication of Edinburgh's Joint Carers' Strategy (2014-17), Scottish Government statisticians considered the range of estimates and concluded that the most robust estimate was provided by the Scottish Household Survey (SHeS) – a figure of 65,084 in Edinburgh, or 13.7% of the population. This is a substantially higher figure than the estimate from the Census alone, which counted 37,859 carers or 7.9% of the population. (Source: Scotland's Census (2011); SHeS (2011))

Table 1: Revised estimated number of unpaid carers split by locality (2011)

2011 Census figures uprated to SHeS Estimate	Locality				Edinburgh
	North East	North West	South East/Central	South West	
Carers (1+ hours/week unpaid care	14,411	20,803	14,659	15,211	65,084
% Carers	13.4	15.5	11.7	13.9	13.7
All People	107,924	134,527	124,930	109,245	476,626
Provides 1 - 19 hours unpaid care a week	8,582	13,296	9,868	9,749	41,495
Provides 20 - 34 hours unpaid care a week	1,224	1,664	1,093	1,265	5,246
Provides 35 - 49 hours unpaid care a week	1,195	1,484	875	1,030	4,584
Provides 50+ hours unpaid care a week	3,411	4,360	2,823	3,167	13,761
% of carers providing 50+ hours/week	23.7	21.0	19.3	20.8	21.1

Source: Scotland's Census (2011); SHeS (2011)

The estimates show that there were proportionally more carers in **North West** (15.5%) than in **South Central** (11.7%). Just over 1 in 5 (21.1%) of carers provide 50+ hours per week and this rate was highest in **North East** (23.7%) and lowest in **South East/Central** (19.3%).

#### **Estimates of Future Demand:**

Unpaid carers will play a key part in achieving the strategic objective of shifting the balance of care by supporting more people to live at home in the community. It is essential that sufficient support is available to allow them to carry out their caring role while maintaining their wellbeing, especially those carers with a greater risk of poorer health.

A further source of increased demand comes from population growth: NRS predicts that Edinburgh's population will grow by 19% to 505,363 between 2013 and 2033. The number of older people in Edinburgh who will require intensive levels of support is expected to increase by 61% over the next 20 years due to demographic factors alone. The number of people over 85 is expected to almost double by 2032 to 19,294. In 20 years the number of people with dementia could rise by 61.7% to 11,548 people (see Appendix Two for further information).

This strategy (*what we want to do*) outlines Edinburgh's vision and priorities for carers throughout the city with more detail provided in the attached implementation plan (*how we will do it*). All aspects of the development and implementation have been approved either by the Edinburgh Integrated Joint Board (EIJB) or the Children's partnership.

#### Where are we now:

This strategy has been informed by Edinburgh Voluntary Organisations' Council's (EVOC) evaluation of the 2014-2017 Joint Carers Strategy undertaken in 2017, subsequent consultation events (via an on-line survey and face to face events) as well as information from VOCAL's biannual survey of carers, as well as being shaped by the Carers (Scotland) Act 2016 and associated Scottish Government National Guidance.

The Edinburgh Joint Carer Strategy 2014-2017 was developed in partnership with key stakeholders and carers. The effectiveness of the strategy was reviewed independently by Edinburgh Voluntary Organisations Council (EVOC) to measure the impact of the Joint Carers Strategy. The review made six recommendations for the new strategy:

- Focus on Implementation
- Broaden ownership of the strategy
- Maintain the same priorities in the new strategy
- Recognise the fundamental differences of young carers
- Futureproof the strategy
- Measure Impact

#### Summary of VOCAL's survey

VOCAL's carer survey report in March 2018, based on 910 carer responses from a total of 7,984 carer households contacted, identified the following priorities for additional carer support:

With nearly 60% of carers reporting a negative impact on their own health as a result of caring, naming specifically insufficient sleep, depression and social isolation from family and friends, future supports should further prioritise personalised and peerfocused activities focusing on improved physical and emotional wellbeing and an increased focus on social contact and engagement

47% of carers reported that being a carer had made money and finances more difficult – a third are paying for care out of their own savings, a quarter had to reduce their working hours and a further quarter had to give up work altogether. With 75% of respondents being female this highlights the disproportionate financial and economic impact of caring on women, with consequences long beyond the caring role into old age. These findings necessitate measures to support carers early in the caring role with a wide range of income maximisation and financial planning and a stepping-up of work with local employers to identify and support carers in the workforce to enable them to retain paid employment.

One third of carers reported they had never had time away from caring at all. 80% of those who had had opportunities to take time away from caring reported this had made it easier for them to continue in their caring role. These findings support the government's and Edinburgh's focus on broadening out opportunities and access to personalised short breaks.

In all the three key areas above, the survey found that carers of children with disabilities and additional needs reported disproportionally greater negative impacts of caring and greater barriers for accessing support than those in other caring situations. This suggests that parent carers require additional priority measures to reduce ill-health, social isolation and financial hardship through improved access to support.

The package of provisions in The Carers (Scotland) Act 2016 is designed to support carers' health and wellbeing. It makes provision for enhanced carers' rights for support in the caring role, including early identification of carers' needs for support, carers' entitlement to adult carer support plans and young carer statements; the provision of support to carers; the enabling of carer involvement in certain services; the preparation of local carer strategies; the establishment of information and advice services for carers; and for connected purposes. See appendix four for further details.

This strategy has been developed in partnership with EHSCP, key stakeholder partners from the third sector, young and adult carers.

### Where are we going?

City of Edinburgh Council and joint planning partners recognise carers as equal partners in care and support the principles developed in partnership with carers and other stakeholders by Equal Partners in Care (EPiC)<sup>1</sup>. The EPIC principles are:

- 1. Carers are identified.
- 2. Carers are supported and empowered to manage their caring role.
- 3. Carers are enabled to have a life outside of caring.
- 4. Carers are fully engaged in the planning and shaping of services.
- 5. Carers are free from disadvantage or discrimination relating to their role.
- 6. Carers are recognised and valued as equal partners in care.

<sup>1</sup> EPiC was a joint project between NHS Education Scotland and the Scottish Social Services Council aimed at achieving better outcomes for all involved in the caring relationship.

The Edinburgh Carers Strategy is one of a number of strategies under development by EHSCP (Link to Strategic plan) and Communities and Families (Link to plan) with carers identified as a cross cutting theme due to the care they provide for vulnerable people in Edinburgh. The EHSCP aspires to identify carers as soon as possible (preferably at point of diagnosis), signposting them to services for information and advice and, should further support be required, helping identify any specific, unmet, assessed needs in a timely manner to support carer health and wellbeing.

Under the Carers (Scotland) Act 2016 there is provision made for both adult and young carers.

The priorities from the Edinburgh Joint Carers Strategy, reviewed by Edinburgh Voluntary Organisations Council (EVOC) in 2017 were found to still be relevant. These six priorities sit within broad strategic areas with related activities and are outlined in table 1. With more detail contained within the high level implementation plan (appendix one).

- Identifying Carers
- Information and Advice
- Carer Health and Wellbeing
- Short Breaks
- Young Carers
- Personalising Support for Carers

Table 1.	High level priorities and activities
Priority	Activities
1.Identifying Carers	<ul> <li>Point of Diagnosis pathways</li> <li>Awareness raising and publicity for employers and workforce</li> <li>Complete Adult Carer Support Plans and Young Carer Statements</li> </ul>
2. Information and Advice	<ul> <li>Access to services using technology</li> <li>Accessible carer training</li> <li>Welfare benefits advice</li> <li>Self-directed support and other carer grants</li> <li>Advocacy</li> </ul>
3. Carer Health and Wellbeing	<ul> <li>Carer support that offers a range of responses</li> <li>Emotional support and/or counselling</li> <li>Emergency planning</li> <li>Services available all year</li> </ul>

Total Control of the
<ul> <li>Transitions planned and supported. Carer stress</li> </ul>
reduced. Carers supported to make future plans
(Power of Attorney/guardianship), support with,
anticipatory care planning, preventative services,
culturally appropriate services
<ul> <li>Development and implementation of a Short</li> </ul>
Breaks Statement.
<ul> <li>Flexible, responsive and creative short breaks</li> </ul>
Management of short breaks funding
<ul> <li>Respitality and breaks with Third sector</li> </ul>
<ul> <li>Identifying young carers as soon as possible</li> </ul>
<ul> <li>Identifying and improving transition periods for</li> </ul>
young carers
<ul> <li>Work with higher education establishments to</li> </ul>
develop joint plans/strategies
Work with schools in their clusters for joint plans
within localities
<ul> <li>Employment and training support.</li> </ul>
<ul> <li>Completing ACSP/YCS as soon as possible with</li> </ul>
carers
<ul> <li>Signposting to existing services</li> </ul>
<ul> <li>Personalised solutions to carers</li> </ul>
<ul> <li>Supporting carers own solutions</li> </ul>
<ul> <li>Use self-directed support options</li> </ul>
<ul> <li>Carers offered more choice and control to</li> </ul>
support their unmet needs
<ul> <li>Getting It Right for Every Child/Getting it Right for</li> </ul>
Everyone framework used
Use of technology enabled care
o Digital inclusion
<ul> <li>Personalised data stores for carer information to</li> </ul>
reduce the number of times carers have to tell
their and the cared for's "story" and share
relevant information

#### **Principles and Vision for Carers in Edinburgh**

The Edinburgh Health and Social Care Partnership and Communities and Families will focus on working with young and adult carers to develop services that increase personalisation and choices within the communities in which they live to improve individual outcomes. We will support carers as early as possible in order to tackle health inequalities, working holistically, developing preventative interventions to meet carers needs. The City of Edinburgh Council recognises the need to work closely with partners within education, health and the third sector to support and meet the needs of young and adult carers.

We will continue to engage and include carers in the development work streams throughout the life of this strategy, developing tools to measure the impact of the services for carers. Linked to the eligibility criteria and outcomes tool based in the SHANARRI (Safe, Healthy, Achieving, Nurtured, Active, Respected, Responsible and Included) indicators we will measure the impact of the strategy, current services and those developed for carers as a result

In order to improve the implementation of this strategy, future reviews and the ongoing development of services, monitoring of the effectiveness of the strategy and its' implementation will be developed with all partners. Further, partners and the local authority are required to report carer census data to the Scottish Government on an annual basis, evidencing outcomes and the impact of the implementation of act. (See Appendix five for the reporting requirements). Agreed key performance indicators (KPI's) and outcomes will assist in planning for future services as trends, demands and gaps emerge through the analysis of the data. This coupled with partners surveys, feedback data and ongoing consultations with carers will inform all future developments.

# What are the Priorities for Adult and Young Carers in Edinburgh?

'I think carers need to be recognised for the commitment they have made. There is no break from this role and at times it is very hard to feel positive.'

**Identifying Carers:** 

Strategic Objective:

**Outcomes for Carers:** 

Carers will be identified within all community care group settings and as such this policy applies to carers of older people, those with physical disabilities, learning disabilities, children with disabilities, people with addiction, with mental health issues and a range of long term health conditions.

One of the greatest barriers to offering help and support to carers is that many people do not identify themselves as being in a caring role. This applies to young carers and adult cares alike, our consultation data shows that this is still a problem and there is a lack of information to assist with this for carers.

- A holistic approach, wherever possible to identifying carers should be encouraged to avoid a 'silo' approach to working with the family.
- Working with partners in
- Identify carers as early in their caring role as possible through school clusters, statutory provision, GP practices, NHS services, Third sector organisations
- Adult Carer Support Plans/Young Carer Statements can be completed and support needs identified at earliest opportunity improving outcomes.
- Carers report being identified early and supported in the workplace to

education, NHS and the third sector in Edinburgh families requiring support, for example, after a diagnosis from an NHS team/GP etc will be offered an **Adult Carer** Support Plan/ Young Carer Statement at that point so new carers not yet fully aware of their caring role are supported early in their journey. This support will continue for as long as the carer requires it and any support offered must be flexible enough to respond to the changing needs of carers. **Employers and** 

 Employers and private sector partners play an increasingly significant role in identifying carers among their workforce and clients, recognising their

- partnership initiatives with Edinburgh employers to identify and support carers in the workplace and to help recruit carers back to work
- Improve carer awareness information to target 'hidden' carers not already identifying as a carer but requiring support.
- Produce a variety of information in a range of formats to widen reach to the target audience as much as possible.

balance caring with employment

role in supporting carers to accessing information and support early in the caring role and allowing them to balance the caring role with paid employment.



## Information and Advice:

#### **Strategic Objective**

#### **Outcomes for Carers:**

The recent consultation with adult and young carers demonstrated that both groups concluded there is no one size fits all solution. Rather, there is a need to develop a variety of information, in a variety of formats and re-doing what has previously been done is not the outcome they want.

We need to work with carers to look at a range of information and advice, for example, young carers produced the short film We Care Do You? (Link) and adult carers in a group cautioned about producing information with the word 'carer' in it as people often don't identify as being a carer. Up to date, relevant information for carers available when they need it, reflecting what carers have said they need.

Information and advice needs to be dynamic in nature responding to the ever changing wider marketplace of social care linking to Welfare Reform changes, Self Directed Support options and opportunities for example. Carers and

- To continuously develop high quality information for carers and professionals in a relevant format using different communication methods.
- To continue to develop and deliver training on carer awareness and other relevant
- Carers have information in a relevant, appropriate, accessible format which is up to date.
- Carers can report they are well informed about issues relevant to their caring role.
- Carers feel supported by services and have increased

practitioners
need to be
updated and
informed in
order to make
informed
decisions
regarding what
they need to
support them in
their caring role.

Of equal importance to developing a range of information and advice solutions is ensuring information and advice is available to carers when they require it and not, for example, at periods of high stress. Therefore, a simple and clear approach for carers to access

information when they

needs.

require it needs to be developed to meet the wide range of carers

- topics relating to the caring role for professionals and carers.
- To continuously engage with carers of all ages on the information and advice they require to support them in their caring role.
- confidence in their caring role.
- Carers are offered help with their financial planning, benefits advice and general advice.
- Carers are informed and integral in hospital discharge plans for the person they care for.

I myself have no support network whatsoever and feel very isolated.

(Unpaid carer 2018)

## Carer Health and Wellbeing:

#### **Strategic Objective**

#### **Outcomes for Carers:**

The role and identity of those within a caring role is a complex one and one not often planned for. Becoming a carer can be a slow process as health gradually deteriorates or as a result of sudden unexpected events with life changing consequences that/which changes lives overnight. No carer is the same and therefore there is no 'one size fits all' solution to carer health and wellbeing.

The challenge for local authorities and their partners is to develop solutions that have enough flex to meet the larger health and wellbeing needs whilst delivering personal outcomes for individual carers regardless of their age. Being a carer can bring considerable challenges however, there are positive

- To identify carers as early as possible in their caring role in order to offer support as soon as possible should it be required.
- To continue to make carer health and well-being a priority offering support that meets their needs to improve health and wellbeing
- Reduce carer stress by offering support that meets their needs as soon as possible in their caring role.
- Carers report improved health and wellbeing, including mental health.
- More carers report improved support within their workplace

- elements to caring for someone you care deeply about and this should not be lost in the mix.
- This section would benefit from mention of several interventions and supports which directly contribute the health and wellbeing, e.g. befriending (this is service now funded by CEC grants, provided by the Eric Liddell Centre), similarly complementary therapies, health checks for carers and healthy lifestyle activities.
- outcomes, including adult education
- We will work
   with employers
   within the city
   of Edinburgh to
   increase their
   carer
   awareness and
   work with them
   to promote
   awareness of
   carer friendly
   policies in the
   work place.
- To develop responses to carer requests for support that are flexible and meet changing carer needs depending on their personal circumstances, for example befriending and counselling services.
- We will work with carers who's caring role has ended either through bereavement or change in circumstances to support them with this transition.

Giving me free time & a break as not really had a proper holiday since taking on the carer role. (Unpaid carer 2018)

#### **Short Breaks:**

#### **Strategic Objective**

#### **Outcomes for Carers:**

The recent consultation with adult and young carers clearly evidenced short breaks and breaks from caring as a key priority. We know from carers feedback that short break options need to be flexible, individual and meet personal outcomes.

The consideration of a carers need for a short break is a requirement of the Carers Act so all carers receiving a ACSP/YCS should have their individual needs discussed in relation to getting a break from caring.

 There are a number of 3<sup>rd</sup> sector partners and statutory services providing a range of short breaks for carers in the city. This

- To identify carers who are in need of a short break
- Deliver a range of short break options
- Promote short break options through the Short Breaks Services Statement and Short Breaks Booklet
- Improve access to short breaks
- Use short breaks as an early intervention

- Improve carers physical health and mental wellbeing
- Increased ability to cope and feeling better supported
- Increased ability to maintain the caring relationship and sustain the caring role
- Improve quality of life
- To provide opportunities to provide a life outside and/or alongside the caring role

can include	that reduces	
options that offer	the likelihood	
breaks from a	of carer/family	
few hours to 7	breakdown or	
nights away; for	crisis.	
the carer alone;		
for the carer and		
the cared for		
person together;		
for a group of		
carers together;		
for the cared for		
person alone		
and/or a		
combination of		
all of these.		

Awareness and knowledge in schools so that better support can be delivered.

(Young Carer 2018)

#### **Young Carers:**

#### **Strategic Objective**

## Outcomes for Carers:

Young Carers are young people first. It is important to remember that each young carer themselves is a unique individual. A child or young person who is entitled to find and reach their full potential.

- There are various circumstances that can arise within the home environment that makes a child or young person a carer. Such circumstances can occur at various points and times within a child or young person's life.
- A young carer is entitled to a childhood.
   Therefore, acknowledgement and recognition needs to be given regarding their caring role and how this impacts on their childhood, adolescence and onto adulthood.

- Ensure all young carers have the best possible childhood and are supported to fulfil their potential.
- To provide training across all sectors i.e education, health to better identify young carers as early as possible
- To implement support networks from partners across the city, accessible for all young carers
- Recognise that YP need support and respite in order

- intervention
  will mean
  better
  outcomes for
  young carers
  in all areas
  of their life;
  social,
  education,
  home
  environment,
  community,
  support
  networks.
- A choice of support, equal and accessible for all young carers across the city such as: support in school, peer support in a group setting, 1:1

- The earlier a young carer is identified the better as this can provide crucial support to alleviate the impact caring can have on a young carers life.
- to reduce the burden of caring on the young carer
- Reduce the likelihood of young carers becoming accommodated
- Give young carers the opportunity to have their say and take action on their individual needs and their rights as a young person
- Give young carers the transition within education, further into relevant adult carer services that meet their needs as young people

- support, drop ins, websites.
- Reducing isolation and the impact of caring as an adverse childhood experiences.
- Being part of a wider nurturing environment with at least one trusted adult in their life
- To feel listened to and have access to holistic support as and when they want to access it
  - Young carers health and wellbeing improves as they are supported through major milestones that can cause additional stress in their

	personal
	circumstance
	<ul> <li>Improved</li> </ul>
	mental
	health and
	general
	wellbeing of
	young
	carers.

To look at each person individually and not one size fits all approach in the adult service.

(Unpaid Carer 2018)

# Personalising Support for Carers:

#### **Strategic Objective**

#### **Outcomes for Carers:**

The Social Care (Self-directed Support) (Scotland) Act 2013 and the Carers (Scotland) Act 2016 have paved the way for the personalisation of carer support, recognising that the support needs and aspirations of people in need of care and their carers vary greatly and no two caring situations are the same.

In the recent consultation on the impact of the Edinburgh Joint Carers Strategy 2014-2017 only 18.42% of carers reported being satisfied with the support they received. Carers indicated that faster assessments, less red tape and formalising informal supports would be required to personalise support.

This strategy recognises the need to define personal outcomes and care solutions jointly with carers, speed up and

- Carers have a better understanding of the choices and support options available to them and how to access them
- High quality ACSP/YCS identify needs and personal outcomes
- Services and supports can respond to needs more flexibly and creatively
- The uptake of SDS options and

- Carer report being listened to and heard
- Carers report feeling well supported throughout their caring journey
- Carers report being supported in care planning and choosing care options best suited to meet their personal needs
- Carers report increased confidence in shaping services for themselves and those they support and more in control

simply access to
support and to offer
support earlier in the
caring role. This will
help strengthen
carer resilience,
mental and physical
health and wellbeing
and carer confidence
to balance and
combine the caring
role with education,
employment and
regular breaks from
caring.

- personalised budgets increases.
- Support is offered timeously and at the earliest possible point in the caring journey to aid prevention, maintain carers' health and reduce the risk of crisis and breakdown of caring relationships
- of the support they receive
- Carers report positive outcomes from personalised budgets

## How will we get there?

There is a lot of work to be done to develop services and resources that meet both young and adult carers needs. However, what is clear is that we do have good services in place now and when carers find them they meet their needs. However, there remains a significant gap in how people find out about support and current services and this was evident from the information provided by carers during the consultation. Therefore, we must look at how we provide information to carers acknowledging that there is no one size fits all solution to this or many of the gaps identified. We will work with professionals and carers to develop services that are responsive and meet carers needs in a timely fashion.

The Scottish Government provided additional financial resources to implement the act. (See table 1.) over the next five years.

Edinburgh Allocation	2018/19	2019/20	2020/21	2021/22	2022/23
Provision of ACSPs	£153,000.00	£482,368.00	£702,160.00	£1,362,374.00	£1,582,165.00
Provision of YCSs	£18,000.00	£36,073.00	£67,112.00	£97,312.00	£128,352.00
Information and Advice	£277,000.00	£255,026.00	£255,026.00	£255,026.00	£255,026.00
Duty to Support adult Carers	£312,000.00	£833,447.00	£1,432,757.00	£3,044,200.00	£4,296,678.00
Duty to Support young Carers	£61,000.00	£122,898.00	£245,798.00	£368,697.00	£544,698.00
Additional Short Breaks Support	£198,000.00	£197,980.00	£197,980.00	£197,980.00	£197,980.00
CIS	£420,000.00	£419,702.00	£419,702.00	£419,786.00	£419,869.00
Local Carer Strategies	£27,000.00	£0.00	£0.00	£13,424.00	£0.00
TOTAL	£1,466,000.00	£2,347,494.00	£3,813,494.00	£5,758,799.00	£7,424,768.00

(Table 1. Estimated Five Year Scottish Government Settlement)

How people access support and advice needs to be streamlined and Adult Carer Support Plans and Young Carer Statements carried out by a range of carers organisations and relevant teams to meet carers needs. There are significant cultural and systems change required for this approach to work and this is currently underway.

Carers have asked for responsive, flexible services that can meet their assessed needs providing, sometimes multiple solutions, to support them within their caring role. Supporting carers within current provision or identified assessed needs alongside staff who understand their situation and personal circumstances is important to carers. In order to meet these needs trained frontline staff will carry out Adult Carer Support Plan and/or Young Carers Statement referring to social work practice teams where required (critical and substantial result or risk concerns). This reduces the pressure on practice teams increasing the responsiveness of services to meet the needs of carers as early as possible.

We will work with council, NHS, education and third sector partners to continuously seek ways to help carers identify they are in a caring role – this will be an ongoing development.

The strategy will be monitored throughout its' life measuring both outcomes and outputs to make sure we are reaching as many carers as we can throughout the city of Edinburgh. We will review the strategy halfway through its' life in order to maintain its relevance to the changing needs of carers and we will continue to work with carers throughout the implementation and review cycle.

Last word to the carers who helped shape this strategy during recent consultation events;

Better understanding... a great many carers are spouses/partners and view caring as a duty, without any skills, or real understanding of the impact this has on not only the relationship but mental and physical health

Not to be treated like imbeciles and to be listened to more. Not to have to fight for everything.

Draft Edinburgh Joint Carers Strategy 2019 – 2022



## Implementation Plan (High Level)

## **Appendix One**

#### What adult and young carers can expect

Areas of Life	Issues	How this plan will help.
Health and Wellbeing	The emotional impact of caring - more	Developing a short breaks statement.

	emotional support required.  Carers' physical health affected  Carers seek mental health support (People to talk to, support to overcome stress, worry, depression)	<ul> <li>Develop and communicate clearer pathways to access services</li> <li>Identify carers/help carers identify as a carer as early as possible</li> <li>Provision of peer mentoring and more peer support programmes</li> <li>Commitment to increased provision of carer counselling</li> </ul>
Relationships	<ul> <li>Change of relationships as a result of the caring situation, the impact of long term conditions, behavioural changes, growing resentment or family relationships, (wife to carer for example).</li> <li>Strained relationships</li> </ul>	<ul> <li>Earlier identification of carers to offer ACSP/YCS at earliest opportunity.</li> <li>Established relationships with carer organisation(s) once identified for ongoing support</li> <li>Provision of peer mentoring and more peer support programmes</li> <li>Access/signposting to counselling services where required.</li> </ul>
Finance and economic wellbeing	<ul> <li>Reduced Income</li> <li>Limited additional resources available.</li> <li>Additional costs of caring</li> <li>Fuel poverty</li> <li>Debt or money worries.</li> <li>Reconciling paid employment with caring responsibilities</li> </ul>	<ul> <li>A range of income maximisation services provided by carer agencies and other services</li> <li>Access to legal information and support for carers.</li> <li>Joint partnership initiatives between carer agencies and employers to identify and support carers in the workforce</li> <li>Training programmes on a wide range of financial</li> </ul>

Life Balance	<ul> <li>Loss of identity</li> <li>Feeling isolated/trapped within caring environment.</li> <li>Little or no chance to socialise.</li> </ul>	planning, access to benefits and income maximisation and self-advocacy  Access to support to make informed decisions regarding financial/ employment planning.  Assisting carers to return to work, incl. access to volunteering  Developing of a short breaks statement  Signposting to relevant carer/other support services.  Early identification of needs through ACSP/YCS and offer of support.  Provision of peer mentoring and more peer support programmes  supporting people to access and benefit from mainstream services —with focus on role of Edinburgh Leisure and also access to personalised budgets
Future Planning	<ul> <li>Power of Attorney Planning.</li> <li>Employment advice</li> <li>Training opportunities</li> <li>Emergency Planning</li> <li>Careers advice</li> </ul>	<ul> <li>Information and advice services – no 'one size fits all' solution.</li> <li>Support peer support groups and activities for carers.</li> <li>Needs identified at the earliest opportunity by the relevant person.</li> <li>Inclusion of emergency planning in ACSP's and</li> </ul>

		good conversations with carers.
Employment and Training	<ul> <li>Unable to work at all.</li> <li>Reduced hours of work.</li> <li>No time to attend training.</li> <li>No money to attend training</li> </ul>	<ul> <li>Information and support for employers regarding carer needs.</li> <li>Support to attend training as identified in ACSP/YCS.</li> <li>Information and signposting to support available</li> <li>Organisations encouraged to be part of the Carer Positive scheme.</li> <li>Assisting carers to return to work, incl. access to volunteering</li> </ul>
Living Environment	<ul> <li>Adaptions</li> <li>Telehealth Solutions</li> <li>Location</li> <li>Housing!!</li> <li>Fuel poverty</li> </ul>	<ul> <li>Information and Advice on housing rights and options</li> <li>Work with housing colleagues</li> <li>Telehealth Services/technology solutions</li> <li>Equipment store links.</li> <li>Home safety checks; energy efficiency checks; telecare checks</li> <li>Personalised budgets for equipment/ assistive technology/ housing repairs and redecoration/gardening</li> <li>Expansion of care and repair handyman service; gardening support?</li> </ul>

Education	<ul> <li>Lack of awareness of young carer needs in schools.</li> <li>Transitions</li> <li>Lack of training for teachers.</li> <li>Lack of consistent information.</li> </ul>	<ul> <li>Needs identified in ACSP/YCS</li> <li>Staff training</li> <li>Clear pathway in schools for accessing support.</li> <li>Young carers supported in school, college and university.</li> </ul>
Breaks from Caring	<ul> <li>Sustaining caring role</li> <li>Stress</li> <li>Risk of inappropriate behaviour due to lack of support</li> <li>Reducing isolation</li> <li>Enhancing a life outside of the caring role</li> <li>Reduce the negative impacts of caring</li> </ul>	<ul> <li>Inform carers about short breaks</li> <li>Utilise Short Breaks         Services Statement and         Booklet to promote good conversations</li> <li>Support carers to access a range of short breaks</li> <li>Support development of short breaks for carers</li> </ul>

#### o Self-care, self-management and self-directed support

These concepts underpin all health and social care directions and we should include a comprehensive section to stress that these underpin the strategy and all interventions and support should focus on reducing dependency, increasing self-directed support and self-help.

SDS must be particularly prominent to reflect recent audit reports and new SG initiatives to roll out SDS options, etc.

#### Social inclusion

We ought to stress the role of mainstream services to be more carer aware and more carer 'friendly' – should Edinburgh develop a 'carer friendly' mark like the 'dementia friends' which would be distinctly different to the carer positive mark? The focus on mainstream services also links to respitality and perhaps the development of a carer discount card. The strategy's aim is to embrace the importance of the wide range of agencies, businesses and employers to play their part, not to focus on a silo of carers.

#### Economic wellbeing

This strategy urgently needs a **comprehensive section on economic wellbeing**: the impact of caring on people's income and the poverty spiral many are exposed to when reducing or giving up work. Financial planning with carers, support for debt management, income maximisation etc are a key aspect of current government focus following the devolution of 15% of the UK's welfare benefits. Edinburgh cannot be seen not to acknowledge this at a time where government and council develop their own anti-poverty strategies!!

 Regarding carer evidence, the strategy should reference VOCAL's most recent carer survey which set out many clear messages from carers – this was discussed and agreed within the Carers' Strategic Partnership earlier this year, just prior to Wendy Dale relinquishing her role as convenor of the group.
 It is desirable to also include reference to surveys or carer evidence produced by other local agencies.

#### Reporting to meet the criteria of the SG Carer Census

We will be expected to reference the government's requirement to report to the Carer Census and we should welcome this initiative and set out in the strategy how we will comply and how we are committed to using the emerging data for future reference, benchmarking and planning of carer support in Edinburgh

#### future/emergency planning

future planning and emergency planning are key aspects for prevention! They feature strongly in the Carers Act and should be raised prominently in the relevant section of the strategy – all agencies need to focus on care planning with carers to help deliver prevention.

Anticipatory care planning - linking up to the NHS KIS summary not just social care. Ensuring that the emergency plan is not just about cared for person but the carer as well. The Enable tool is very cared for person dominated. We should point to the importance of estates planning to capture ideas of wills, trusts.

We need to stress the need for more guardianship and Power of Attorney work – lack of POA/Guardianship arrangements are often at the heart of long

delays for hospital discharge and other key decisions needing to be taken in the interest of a person – there is a growing need for more POA and guardianship work!

#### IT and digital skills and literacy

The strategy should emphasise the need to assist carers with initiatives to increase their digital and IT skills – Longstone is a case in point; communication and self-help through internet and social media are crucial for training, information and social inclusion, etc. The digital dimensions of future support provision deserve a section and would include assistive technology/telehealth

#### What we know

#### **Appendix Two**

It is estimated that around 788,000 people are caring for a relative, friend or neighbour in Scotland including 44,000 people under the age of 18<sup>[6]</sup>. The provision of unpaid care to family members, friends or others is not shared equally across social groups. Also, the mental and physical health and wellbeing of carers can be negatively affected by the caring demands placed upon them; around a third of carers have reported that caring has a negative impact on their health and the more care that a carer provides, the less likely they are to report good health<sup>[6]</sup>.

The Scottish Health survey found that 47% of the Scottish population had a long term condition, 53% of that number are female and 47% are male. The prevelance of limiting long-term conditions was highest for those aged 75 and over and lowest for those aged 0-15.

The prevalence of long-term conditions therefore represent significant personal, social and economic costs both to individuals and their families as well as to health and care services and Scottish society more widely.

(Scottish Health Survey 2016: volume 1: main report: <a href="https://www.gov.scot/publications/scottish-health-survey-2016-volume-1-main-report/pages/60/">https://www.gov.scot/publications/scottish-health-survey-2016-volume-1-main-report/pages/60/</a>)

#### The Scottish Health Survey (2016) indicated that;

- More than one in seven (15%) adults provided regular, unpaid care to a family member, friend or someone else in 2016, with women more likely to do so than men (17% and 13% respectively).
- Of all children aged 4-15, 3% provided care, with older children more likely to provide care than younger (5% of those aged 12-15 compared with 1% of those aged 4-11).
- Women working full time were significantly more likely to provide unpaid care than men working full time (17% and 12% respectively).
- In 2015/2016, adults providing unpaid care were most likely to do so for 5-19 hours per week.
- Those over the age of 65 were most likely to provide more than 50 hours of care per week at 24%, compared with 13-14% of those aged 16-64.

So we know that one in ten young people are carers and one in seven adults provide unpaid care, this can have several impacts both positive and negative for carers across Edinburgh. (More detail can be found by following this link -

https://www.gov.scot/publications/scottish-health-survey-2016-volume-1-main-report/pages/60/

#### **Appendix Three**

## What information informed this version of the Edinburgh Joint Carers Strategy?

#### Review of currently commissioned services and grant reviews.

This version of the strategy incorporates the learning from the previous Edinburgh Joint Carers Strategy (2014-17) and the subsequent independent review and recommendations made by EVOC. Services currently commissioned by Communities and Families and the Health and Social Care Partnership were also reviewed to inform this strategy preventing the duplication of any services developed using the funding available. The new grants processes will also influence the implementation of the strategy and will impact on both small grass root services and larger city-wide services.

#### City wide consultation of carers

In order to develop a strategy and implementation plan that is relevant to current needs of carers the EHSCP and its partners carried out a joint and independent consultations. VOCAL carried out a carer survey of 8,000 carer households with 915 carer responses in November 2017, commissioned by VOCAL and conducted independently by ScotInform (https://www.vocal.org.uk/wp-content/uploads/2018/03/2017-VOCALCarerSurveyReport\_Edinburgh.pdf)

The city-wide consultation on the Carers (Scotland) Act 2016 was for unpaid carers and targeted at Young Carers and Adult Carers alike. The initial information gathering was completed using a short Survey Monkey distributed electronically via partner organisations and the City of Edinburgh Council's consultation hub.

Once the online survey was closed three officers met to discuss some high-level themes that had come from the 126 responses received. Face to face events were then planned open to both young and adult carers to check out the themes identified and record more specific points discussed – these events were attended by 5 adult carers and 19 young carers. A further 4 events were carried out in partnership with young carer organisations to collect young people's views – these were attended by 50 young carers.

#### **Appendix Four**

#### Summary of key themes from Carers (Scotland) Act 2016

- Widening the definition of carer so it encompasses a greater number of carers.
- Placing a duty on local authorities to prepare an adult carer support plan
   (ACSP) or a young carer statement (YCS) for anyone who requests one or is
   identified as a carer. As part of an ACSP/YCS the development of an
   emergency plan and carer's need for short breaks from their caring role must
   be considered and recorded.
- Giving local authorities a duty to provide support to carers who meet local eligibility criteria.
- Requiring local authorities and NHS boards to involve carers in the development of carer services and hospital discharge processes for the people they care for.
- Giving local authorities a duty to prepare a carers strategy for their area.
- Requiring local authorities to establish and maintain advice and information services for carers.
- To prepare and publish a statement on short breaks available in Scotland for carers and cared for persons.

#### What data is collected in the Carers Census?

#### For each Carer:

- Data Provider
- ID Carer
- CHI number
- postcode
- date of birth
- gender
- ethnic group
- care duration
- care hours
- care type
- care impact

#### For the person they care for:

- ID Carer
- Unique ID for cared for person
- age group
- does carer live with cared for person
- gender
- ethnic group
- client group
- relationship to carer

## For Adult Care Support Plan / Young Carers Statement:

- ID Carer
- source of referral for ACSP / YCS
- date ACSP / YCS requested / offered
- type of ACSP / YCS new or review
- ACSP / YCS completed?
- date completed
- ACSP / YCS declined
- date declined
- ACSP / YCS joint assessment with cared for person
- is carer willing to care
- is carer able to care.
- is carer eligible for support
- carers support needs
- support provided / purchased by LA
- did review result in change to support
- Short break provided
- Number of short breaks taken
- Replacement care provided
- Type of replacement care
- Daytime replacement care hours
- Overnight replacement care nights

For Young Carers Statement: responsible Authority for young carer

#### Please note:

Items in pale text are not mandatory for 2018-19 but we would encourage you to return these if you already hold this data as this will help with discussion on taking forward data collection for these items which are still considered essential for the longer term data collection.

