

# Policy and Sustainability Committee

10.00, Tuesday 22<sup>nd</sup> August 2023

## Policy for Supporting Adult Carers and Caring Relationships

Routine  
Wards: All  
Council Commitments

### 1. Recommendations

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1.1 It is recommended that Policy and Sustainability Committee:

1.1.1 Approves the Supporting Adult Carers and Caring Relationships Policy.

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## Policy for Supporting Adult Carers and Caring Relationships

### 2. Executive Summary

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- 2.1 It has been identified that the Edinburgh Health and Social Care Partnership (the Partnership) lacks a formal policy on supporting adult carers and caring relationships.
- 2.2 To address this, a new policy has been developed which determines the Partnership's vision and commitment to supporting adult carers within their caring relationships and improve or maintain their health and well-being through a variety of pro-active and planned supports.

### 3. Background

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- 3.1 Policy, strategy, and procedure interrelate:
  - 3.1.1 A policy is a statement of intent which details the organisational aims and guiding principles.
  - 3.1.2 A strategy is the overarching plan which supports delivery of the organisational aims and considers the resource required.
  - 3.1.3 A procedure details specific actions, methods and processes to guide implementation of the policy.
- 3.2 The Carers (Scotland) Act 2016 (implemented 1<sup>st</sup> April 2018) extends and enhances the rights of carers with an aim of better supporting caring relationships and promoting the health and well-being of unpaid carers, the supported person, and other family members affected by the caring situation.
- 3.3 The Joint Carers Strategy for Edinburgh was approved by Edinburgh the Integration Joint Board (EIJB) in August 2019 and is currently under review. The revised Joint Carers Strategy was approved by the EIJB on 8 August 2023.
- 3.4 In addition to not having a policy for adult carers, the operational procedure (2013) and the Short Break Services Statement (2019) require an update.
- 3.5 A short life working group to develop the policy on supporting adult carers and caring relationships was created to ensure a collaborative approach and stakeholder engagement.

## 4. Main report

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- 4.1 Adult carers contribute significantly to providing help and support to family, friends or neighbours who cannot live independently. It is crucial that the Partnership has clear direction in supporting positive and sustainable caring relationships.
- 4.2 It is widely recognised that unpaid carers have been significantly affected because of the Covid-19 Pandemic. There remain challenges in delivering services, particularly in relation to recruitment and retention of staff which is impacting on the ability of Carers to have a break from caring, primarily where there is a need for replacement care.
- 4.3 Historically, the operational procedure has mostly focused on services rather than personal outcomes. Shared Care Scotland (a national carer organisation contributing to policy development and best practice for carers) highlight the importance of short breaks being defined and interpreted as broadly as possible to support choice and encourage creativity.
- 4.4 Developed and co-produced across multiple stakeholders, the policy has been informed locally and reflects key legislation and guidance set out within the Carers (Scotland) Act 2016, and the Social Care (Self-Directed Support) (Scotland) Act 2013; and is underpinned by the principles and approaches of Shared Care Scotland's Promoting Variety Programme.
- 4.5 Further to carer feedback, this new policy acknowledges adult carers may not always have felt recognised and valued for the significant contribution they provide and aims to empower adult carers as partners who are experts in knowing the outcomes they want to achieve.
- 4.6 The Partnership acknowledge the policy is only one element of improvement required in relation to breaks from caring and work is currently underway within the Adult Social Care Improvement Plan approved by the EIJB on 14<sup>th</sup> June 2023 and as part of the Joint Carers Strategy Refresh 2023-26, which is committed to developing a Short Breaks Implementation Plan to continue to develop and deliver wide ranging creative breaks.

## 5. Next Steps

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- 5.1 Once approved, this policy will be implemented by the following:
  - 5.1.1 development of an associated procedure to guide practitioners and partner organisations on implementation (inclusive of learning workshops).
  - 5.1.2 updating the Edinburgh Short Breaks Service Statement 2019 to provide information to carers and cared for people so that they:
    - know they can have a break in a range of ways,
    - are informed about short breaks that are available,

- have choice in the support they access, and optimise self-directed support options,
- can identify what a short break means for them, and how they can be supported to meet their needs and achieve their personal outcomes.

5.1.3 the Short Breaks Implementation Plan, which will:

- seek to build upon the policy, and collaborations between partners and unpaid carers to promote a variety of short breaks,
- optimise availability across partner agencies,
- identify services to be developed to provide high quality short breaks to meet carers strategic and personal outcomes,
- explore options around Short Breaks Brokerage, supporting carers to have an outcomes focused plan, increased knowledge and support to access more short break opportunities and ensure a more balanced life alongside or outside of their caring role.

## 6. Financial impact

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6.1 The overall aim of this policy is to adopt an early intervention and preventative approach, by supporting self-management through access to universal or targeted supports. Not supporting Adult Carers effectively imposes the potential of deterioration in health and wellbeing outcomes; placing carers and those they care for at risk, leading to a point of crisis and reactive responses. It is difficult to determine an exact financial impact of implementing the policy. However, any implications, financial or other will be identified through the development of an accompanying procedure and considered appropriately.

## 7. Consultation

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- 7.1 A wide range of people have been involved in the development of this policy, including unpaid carers, carer organisations, Shared Care Scotland and Partnership representatives.
- 7.2 A carer focus group was facilitated by a local carer organisation (Care 4 Carers) and feedback on the policy (Appendix 2) has further shaped this final version.
- 7.3 An [Integrated Impact Assessment](#) has been completed and published

## 8. Background reading/external references

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- 8.1 [Short Break Services Statement 2019](#)
- 8.2 [Shared care Scotland Promoting Variety](#)

## **9. Appendices**

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- 9.1 Appendix 1 – Policy for Supporting Adult Carers and Caring Relationships.
- 9.2 Appendix 2 – Carer focus group feedback and how this has informed the Policy.

**Appendix 1:**

<b>Policy Title</b>	Supporting Adult Carers and Caring Relationships
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<b>Implementation Date</b>		
<b>Review Date</b>		
<b>Agreed by</b>		
<b>Date Agreed</b>		

<b>Version Control</b>	
1.1	

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## 1. Purpose

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- 1.1. The main aim for Edinburgh Health and Social Care Partnership is to improve or maintain Adult Carers well-being and prevent ill health, with a variety of pro-active and planned supports. These supports should be creative, innovative, sustainable and empower Adult Carers as partners who are experts in knowing the outcomes they want to achieve.
- 1.2. We acknowledge that Adult Carers may not always have felt recognised and valued for the significant contribution they provide in helping and supporting relatives, friends, or neighbours, who cannot manage to live independently without the Adult Carer's unpaid help due to frailty, illness, disability, or addiction.
- 1.3. Adult Carers may have multiple caring roles with a diverse range of cared for people. For many Adult Carers it may not be a role which they have actively chosen and is often life-long. Although Adult Carers experience positive and rewarding aspects of their role; there is also evidence that Adult Carers may have negative experiences. These may affect their physical or emotional health and wellbeing, and consequently their ability or willingness to continue in their caring role.
- 1.4. This policy sets out the Edinburgh Health and Social Care Partnerships' vision and commitment to supporting Adult Carers with their caring relationships to ensure a fair and consistent approach.

## 2. Scope

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- 2.1. This policy will:
  - 2.1.1. provide a definition of an Adult Carer (including Young Adult Carers) which is clear; and recognises the significant contribution provided.
  - 2.1.2. embed the principles of the Three Conversations Approach in supporting Adult Carers and Cared for People.
  - 2.1.3. provide a definition of "Breaks from Caring" which is clear, fair, and equitable for unpaid Adult Carers in supporting their personal outcomes.
  - 2.1.4. provide a definition of "Replacement Care" which is clear, fair and equitable for "Cared for People" to access planned support which meets their personal outcomes, whilst their Adult Carer has a Break from Caring; or in unplanned and crisis situations provide emergency replacement care when the Adult Carer is unavailable.



2.1.5. promote variety, increase flexibility, and improve the choice of supports available within all Self-Directed Support options to meet the personal outcomes of Adult Carers and Cared for People.

2.2. This policy applies to local (*see Definitions*):

2.2.1. Adult Carers (including Young Adult Carers)

2.2.2. Cared for People (*see also 2.3*).

2.3. This policy does not apply for Replacement Care when:

<b>Replacement care out of scope for;</b>	<b>Considerations</b>
People who are living long term in residential care, the Shared Lives Scheme or out of this Local Authority area	Adult Carers with caring relationships to these Cared for People, may have personal outcomes associated with that role which fall within scope
People who are supported by Volunteers provided by a Volunteering service/organisation (i.e., the absence of the volunteer does not automatically qualify the person volunteered with to receiving replacement care or support)	Adult Carers may choose to engage in voluntary and/or paid work as part of their personal outcomes; and this work does not remove the Adult Carer from scope
People who are using Direct Payment to pay an Adult Carer for <u>some</u> elements of their support (paid elements excluded)	Adult Carers are within the scope of this policy for the unpaid aspects of their caring role in which they support the cared for person.
People under the age of 18 who remain in school.	Adult Carers of people under the age of 18 (regardless of whether the person is in formal education or not) may have eligible needs in relation to their caring role and are therefore within scope.

### 3. Definitions

Term	Meaning
Adult Carer Support Plan	Enables carers to discuss the caring role and its impact on their life. The plan can help balance life alongside a caring role. The plan will also set out what supports can help carers achieve the outcomes that are important to them. An Adult Carer Support Plan can also help identify what can be done if a carer feels unable to continue caring.
Break(s) from caring	<p>A break from caring is <u>any form of assistance</u> or service which enables carers to have sufficient and regular periods away from their caring routines or responsibilities. The purpose is to support the caring relationship and promote the health and well-being of the carer, the cared for person, and other family members affected by the caring situation. Breaks from caring should be defined and interpreted as broadly as possible. This supports choice and encourages creativity in meeting carers personal outcomes. Sometimes the term “short break” is used but is more typically associated with some form of replacement care and support for the cared for person, which in turn provides a carer break.</p> <p>Some Adult Carers may want to have breaks from caring/short breaks with the Cared for Person.</p> <p>For some carers a form of assistance or ability to increase their capacity to cope could be enabled by having equipment, technology, training or access to advocacy. Further examples are in the Short Breaks Services Statement.</p>
Brokerage	A term used for sourcing a range of suitable support options which meet people’s personal outcomes. This may include practical items, activities or direct support provision. Those ‘brokering’ support will act as a link between people and resources and have good knowledge and understanding about resources which are locally available. They will work alongside unpaid carers and/ or cared for people to co-produce support that is right for them.
Adult Carer	<p>A person over the age of 18 (who has left school), who provides, or intends to provide, unpaid help and support to a person who is a relative, friend or neighbour who cannot manage to live independently without the Adult Carer’s help due to frailty, illness, disability or addiction. (adapted from “The Carer’s Act (Scotland) 2016”)</p> <p>For the purpose of this policy this includes Young Adult Carers as defined below.</p> <p>Adult Carers may have multiple caring roles; with a diverse range of cared for people.</p>
Cared for Person / People	A person over the age of 18* who cannot manage to live independently without the Adult Carer’s help due to age related conditions, long term impairments or disability, long-term or short-term mental or physical ill health.

	<p>A Cared for Person may not be living at the same address as the Adult Carer.  <i>*16-17 year-olds included if they have left school/formal education</i></p>
Emergency Replacement care	<p>The care and support for a cared for person, that is normally provided by an unpaid adult carer, which requires to be undertaken in a crisis e.g., Adult Carer Severe illness, Hospital admission, or death. Outcomes for emergency replacement care can be met in a variety of ways and models.</p>
Eligibility Criteria	<p>The Eligibility Criteria Policy describes levels of need that fall into 4 categories; critical, substantial, moderate and low need. It also sets out which levels of need we will support through the provision of services and supports using the 4 SDS options. The level of need is determined through an assessment of a person's needs carried out by a professional or other approved person.</p> <p>Eligibility is considered individually for Adult Carers and Cared for People. Although these parties are connected; the Eligibility of one party does not automatically change the Eligibility of the other.</p>
Personalised and Individual supports including replacement care	<p>Individualised support applies to outcomes which cannot be met or provided by universal or targeted support. The purpose of individualised support is to reduce the impact and risks of caring for the carer to a sustainable level. This is arranged through self-directed support for planned replacement care and/ or in unplanned and crisis situation provide emergency replacement care when the Adult Carer is unavailable.</p>
Preventative and Universal Supports	<p>Supports which are open to everyone are provided and guided by local partner organisations and generally already available to support carers to make the best use of the strengths, capabilities and supports already available to them. These types of supports will always be considered first and remain accessible if more targeted or individual supports are required.</p>
Replacement care	<p>Care and support for a cared for person which is normally provided by an unpaid carer which requires to be undertaken to enable the unpaid carer to have a break from caring, either in a crisis or more typically on a planned basis.</p> <p>Outcomes for replacement care and support can be met in a variety of ways and models. These are explained in the Short Breaks Services Statement.</p>
Respite	<p>Sometimes, the term 'Respite' is used to describe a break from caring. 'Respite' is defined as a break from something that is unpleasant. Therefore, most Carers and our partners</p>

	<p>feel the term 'Respite' is negative and is often associated with institutional services or emergency situations. 'Short Breaks' is a term more positive, broader and inclusive and captures the flexibility and creativity that Carers have told us matters to them and will replace the term 'Respite.'</p>
Short Break	See 'Break from caring'
Short Breaks Services Statement	<p>The purpose of a "Short Break Services Statement" is to provide information to carers and cared for people so that they;</p> <ul style="list-style-type: none"> <li>• Know they can have a break in a range of ways</li> <li>• Are informed about short breaks that are available</li> <li>• Have choice in the support they access</li> <li>• Can identify what a short break means for them, and how they can be supported to meet their needs and achieve their outcomes.</li> </ul>
Social Care Direct	First point of contact for people who want to access support.
Targeted and more specialised services	Where Adult Carer outcomes cannot be fully met through preventative or universal support, more targeted supports are available. These are typically more specialised which focus on a particular issue and may require access to services which are already funded by Edinburgh Health and Social care Partnership.
Three Conversations®	<p>The Three Conversations is an approach to having open and engaging conversations with Supported people and their Unpaid Carers about the support they need and working together to co-produce the right support at the right time. Each conversation is a stage and multiple discussions may be required at each conversation point.</p> <p><u>Conversation 1: Listen and connect</u>  Conversation 1 is about listening hard to people and their families to understand what's important and working with them to make connections and build relationships in order to help them get on with their life independently. Conversation 1 is not about whether the person is 'eligible', but it does meet legislative requirements.</p> <p><u>Conversation 2: Work intensively with people in crisis</u>  When we meet people who need something to happen urgently to help them regain stability and control in their life, we use Conversation 2 to understand what's causing the crisis, put together an 'emergency plan' and stick with the person to make sure that the changes happen quickly, and that the plan works for them.</p> <p><u>Conversation 3: Build a good life.</u>  We always exhaust Conversations 1 and/or 2 before moving on to Conversation 3 – and often we find that we don't get this far. But for some people, longer-term support in building a good life will be necessary. Conversation 3 is about understanding what this good life looks like to them and their</p>

	family, and helping them to get the support organised so they can live the best life possible.
Unpaid carer	See Adult Carer.
Young Adult Carer	Young adult carers who are aged 18-25, who have needs around the transition from children and young people's services into adulthood and accessing age-appropriate adult supports. Young adult carers also require support to create a life beyond caring and explore opportunities for employment, further education, or moving into their own homes;
Young Carer	A young carer is a carer who is under 18 years old or is 18 years old and is still at school. Young Carers are not directly in scope of this Policy and are supported by the Communities and Families Department.

## 4. Policy Content

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### Principles of Supporting Adult Carers and Cared for People

- 4.1. Supports should be creative, innovative, sustainable and empower Adult Carers as partners who are experts in knowing the outcomes they want to achieve. This means not fitting people into services, instead, supporting people to identify personal outcomes and ways to enable these to be met through co-producing suitable supports and options.
- 4.2. Identifying personal outcomes and needs of Adult Carers must, take into account:
- personal outcomes may be changeable and require regular review.
  - any impact of having one or more protected characteristics.
  - if they have additional needs specific to being a Young Adult Carer.
  - any socioeconomic factors which prevent or reduce inequalities of outcome, e.g., low income, poverty or inability to access paid employment as a result of caring commitments or other circumstances.
- 4.3. The outcomes and needs of Adult Carers are as diverse as those of Cared for People. Therefore, it is important that the well-being of Adult Carers is given as much consideration as that of the Cared for Person.
- 4.4. We adopt an early intervention and preventative approach by supporting self-management through access to universal or targeted supports (e.g., telecare, information, advice, advocacy, community resources, support partner agencies, translation services, counselling and peer support)

- 4.5. The purpose of a 'break from caring/short break' is to support Adult Carers to have a life outside of, and/or alongside of their caring role. It should help to support their health and wellbeing, sustain their ability to continue in their caring role, be planned around what is important in their life and improve their personal outcomes.
- 4.6. Supports for the cared for person should also meet their personal outcomes and may benefit others (e.g., family members) which can help to maintain and sustain relationships.
- 4.7. Transitions or changing circumstances can impact caring responsibilities and affect the wellbeing of either Adult Carers or Cared for People. Changing circumstances may be short or long term and relate to; age, moving home, leaving or moving towards long term care or hospital, illness or caring for people with terminal conditions. Therefore, Adult Carers should be supported to plan successful transitions and change.

### **How we will approach this**

#### **4.8. Edinburgh Joint Carers Strategy Refresh:**

4.8.1. This strategy is informed by national and local context. It outlines local priorities and associated areas for improvement, outcomes for carers as well as details of the activities needed to achieve them. The strategy supports the Edinburgh Health and Social Care Partnership and Communities and Families to demonstrate impact on Outcome 6 of the National Health and Wellbeing Outcomes, "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."

4.8.2. The strategy focuses on six priority areas:

- Identifying carers
- Information and Advice
- Carer health and wellbeing
- Short Breaks
- Young carers
- Personalising support for carers.

#### 4.9 Voluntary and Independent Sectors:

4.9.1 The voluntary and independent sectors are vital partners in the development of health and social care in Edinburgh. Our partners are faced with similar budgetary and workforce pressures, and it is essential we work together and build trust to make the most of the resources available. Engagement and collaborative planning are central in realising the benefits of these relationships. Both sectors will be invited to continue their support in co-production and planning as services and supports continue to develop and improve for adult carers.

#### 4.10 Adult Carer Support Plans:

4.10.1 Enable carers to discuss the caring role and its impact on their life. The plan should help balance life alongside a caring role. The plan will also set out what supports can help carers achieve what is important to them. An Adult Carer Support Plan can also help identify what can be done if a carer feels unable to continue caring.

4.10.2 May be carried out by Edinburgh Health and Social Care Partnership (through Social Care Direct or Edinburgh Carer Support Team) or one of our partner organisations.

4.10.3 Can be accessed by Adult Carers living out with the local authority boundaries, but who may have caring responsibilities for a person living in Edinburgh.

4.10.4 Will fully consider that Adult Carers may have multiple caring roles; with a diverse range of cared for people. In these circumstances, The Adult Carer Support Plan will identify the Adult Carer's outcomes across all these relationships. Where support for the caring role or replacement care is required within one or more of these caring relationships, the outcomes for each cared for person will be identified individually based on their circumstances. Therefore, individual outcomes are likely to be as diverse as the cared for people's needs.

4.10.5 Should be reviewed on an annual basis alongside planned supports. The positive impact of previous supports should not diminish the requirement for future support; with full consideration given to the impact on the Adult Carer if they were to be changed or reduced.

4.10.6 Once completed, will detail the Adult Carers needs and outcomes. It will also describe how the Adult Carer will be assisted to access supports which are appropriate to their needs and outcomes.

4.10.7 Identified outcomes can be met flexibly across the full range of Self-Directed Support options using the Three Conversations Approach. The level of need is determined through an assessment of a person's needs carried out by a professional or other approved person. Adults Carers can be empowered to access Universal, Targeted or Individual Supports based on their needs:

- any form of assistance or service which enables carers to have sufficient and regular periods away from their caring routines or responsibilities.
- Support in the form of a service or budget for Adult Carers may be agreed based on their individual outcomes.
- Support in the form of a service or budget for Cared for People may be agreed based on their individual outcomes.
- In some circumstances Adult Carers and Cared for People may have shared outcomes which may enable a 'break' together

#### 4.11 Short Breaks Services Statement

4.11.1 The Carer's Act (Scotland) (2016) instructed local authorities to publish a document which describes the Short Breaks options locally available for Adult Carers and Cared for People. Edinburgh Health and Social Care Partnership have published this and it should be reviewed regularly.

4.11.2 The purpose of a "Short Break Services Statement" is to provide information to carers and cared for people so that they:

- Know they can have a break in a range of ways (there are illustrative ideas listed, but options should not be limited to pre-defined lists).
- Are informed about short breaks that are available.
- Have choice in the support they access.
- Can identify what a short break means for them, and how they can be supported to meet their needs and achieve their personal outcomes and more.

#### 4.12 Charges and fees

4.12.1 There is no charge to the Adult Carer for Breaks from Caring/ Short breaks.



4.12.2 Some types of Replacement Care for Cared for People may be chargeable (to the cared for person) in line with Legislation and National Guidance.

#### 4.13 Practitioner Guidance and Toolkit

4.13.1 Training, accompanied by local guidance and procedures will be developed to support practitioners in applying this policy to ensure consistent application.

#### 4.14 Edinburgh Carer Support Team

4.14.1 The Edinburgh Carer Support Team can offer advice, information and support on:

- rights of carers
- local services
- medical conditions and medication
- how carers can look after themselves
- increasing carer confidence
- support carers in setting goals and priorities in their own lives
- developing an Adult Carer Support Plan

## 5 Roles and Responsibilities

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### 5.1 Employees:

- To follow and apply the policy.

## 6 Equalities and Impact Assessment

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6.1 An [Integrated Impact Assessment](#) was carried out for this policy on 07 June 2022 and reviewed on 21 March 2023

## 7 Risk Assessment

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7.1 Not supporting Adult Carers effectively imposes the potential of deteriorating their health and wellbeing outcomes; placing themselves and those they care for at risk. This Policy has detailed the mitigations to address these risks. Further development of a local procedure/ Practitioner guide and update of the Short Break Services Statement will further mitigate any risks.

7.2 Successful implementation is dependent on a collaborative approach across professional groups and organisations. This requires effective assessment, planning and delivery of outcomes which is underpinned by the principles of self-directed support.

## 8 Review

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8.1 This policy should be reviewed annually in line with Edinburgh Health and Social Care Partnership policy framework.

## 9 Legislative Context

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9.1 **The Carers (Scotland) Act 2016** places a legislative requirement to provide support to Carers and offer an Adult Carer Support Plan, which includes considering if a Short Break would help meet the Carer's outcomes. The Act also requires that a Statement is published which sets out information about Short Breaks, including what services are available for Carers and the people they support.

9.2 **The Social Care (Self-Directed Support) (Scotland) Act 2013**, Carers should be provided with information and advice about Self-Directed Support options. If a Carer is eligible, staff must offer and explain a range of choices to them and the person they care for, about how support can be provided.

9.3 **The Social Work (Scotland) Act 1968** is the key legislation for social work services and places the responsibility for these services with local authorities.

Current policy themes in social work are:

- Personalisation and person-centred support, which puts the person first, as an expert in their own care.
- Independent living, which aims to ensure people can live independently and in homely settings for as long as possible

- Early intervention and prevention, which aims to take action to avoid problems escalating and requiring more intrusive or intensive services
- Joined up working, which encourages smooth and collaborative working across relevant organisations

**9.4 Community Care and Health (Scotland) Act 2002** introduced free personal care for adults, regardless of income or whether they live at home or in residential care.

## 10 Related Documents

10.1 [Short Break Services Statement](#)

10.2 Edinburgh Joint Carers Strategy Refresh

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## Appendix 2

### Supporting Adult Carers and Caring Relationships Policy

#### Unpaid Carer Focus Group Feedback Summary

A Carer Focus Group was held on 24<sup>th</sup> February 2023 with the purpose of consulting on the draft 'Supporting Adult Carers and Caring Relationships' Policy. The event was widely publicised by Care 4 Carers through the Carers Strategic Partnership Group and the Edinburgh Carers Forum. The background to the development and the intentions of the policy was detailed by Edinburgh Health and Social Care Partnership representatives and the event was facilitated by Care 4 Carers, with people in attendance sharing a broad range of views on behalf of:

- Unpaid Carers
- Carer Organisations
- 3<sup>rd</sup> Sector professionals
- Integration Joint Board Carer representative
- Edinburgh Health and Social Care

The Partnership would like to thank Care 4 Carers and everyone who attended and contributed to the event. The feedback received has been invaluable, not only in further shaping the policy but also informing how the policy is implemented through organisational procedure.

Care 4 Carers provided written feedback from the event and further shared additional information afterwards. This has been collated and shared below, alongside the Partnerships comments on how the feedback will either:

- ✓ Inform further development and amendments to the Policy.
- ✓ Inform the development of the procedure or update to the Short Break Services Statement.
- ✓ Be shared with the Carers Strategic Partnership Group and Planning and commissioning colleagues.

#### What people felt were positive aspects of the policy:

- Having this policy will help to bring everything together.
- This is like Terms and Conditions for Carers Short Break Planning & Services. Good thing to promote consistency of approaches towards short breaks for carers from across sectors, professionals, staff, carers organisations etc.
- There is more of a family centred approach and an aim to have earlier intervention.
- Like the clarity of the definitions, and the language feels accessible.
- The process of the Adult Carer Support Plans is set out very clearly.
- It is positive that the policy highlights carers having multiple roles as this encapsulated the person-centred approach.
- This has been a long time coming!
- There is a focus on best practice.
- Focussing on people rather than service does come through.
- It is positive that the policy recognises that a carer may not live at the same address as the cared for person.
- Glad that there is work being done to bring it up to the 21<sup>st</sup> Century and that there is some recognition about what carers do.

### What people said about Accessibility:

- It would be good to have a visual, illustrated example or version of the policy.
- Accessible versions – easy to read; languages; visually impaired.
- Spanish/Arabic/Urdu/Polish – would be good languages for the policy to be translated to. Would it be possible to have a condensed
- Summary translated? Or Targeted translation? (A cost-effective option).

### We will:

- ✓ Arrange for an easy read version to be developed.
- ✓ On publication, include details of how to access the policy in alternative formats e.g., large print or translated into an alternative language.

### What people said about the language used:

- The language is legal and formal which may be required for a policy, but it doesn't make it easy to read and understand. How about a plain English version! What does Brokerage mean?
- The wording of the policy is sufficiently vague – trying to pin it down any more could end up restricting who is impacted.
- Remove jargon and acronyms or put definitions at front
- It seems like the words in italics expressed the meaning better for example 2.3
- Section 1.2 - statement made some of the group angry and patronised.
- Section 1.3. the group felt this needs to change. It was noted that it is good to have their role recognised but for many it has to be understood that becoming a carer is often not a choice and it is 24/7 and forever.
- Section 2.2.3 – What does 'who have a break from caring outcomes' mean? Would be clearer if it was replaced with something like ... 'for Adult Carers who need a break from caring'

### We will:

- ✓ Review and simplify the wording.
- ✓ Include brokerage within the definitions section.
- ✓ Remove all acronyms.
- ✓ Change section 1.2 and 1.3 to acknowledge carers don't always feel recognised and for many there is no choice in the caring role.

### What people said about the policy content:

- Confusion 2.3 around who it applies to, who actually is the beneficiary.
- Section 2.3 - This is really confusing, too many negatives, not/ do not. Format changes don't help. Just tell us who the policy does apply too, that would be easier to read and understand.
- The group felt that it was not completely clear about 'who is a carer'.
- The focus still seems to be geared towards the cared for person.
- Include a sentence about the purpose of a break also being to sustain the carers ability to continue caring and to avoid carer breakdown, exhaustion and burn out.
- Section 4.5 - Transitions need to include all stages of life, so Hospital Discharge at home or places of care, interim or long-term changes. These have a massive impact on carers especially when the cared for persons needs have radically changed. The support needs for the carer should be reassessed at these transition points as a matter of routine.
- Policy needs to better reflect multiple and complex caring roles and an aging demographic both in carers and the people they care for.
- Can we say 'personal outcomes for carers' not sure what Outcome focussed means? Personal outcomes might be easier to relate to
- Often, the people that need care and carers fall under 'marginalised' groups. There are already lots of barriers in place for people within marginalised communities e.g., not being registered with a GP. Is there any way to acknowledge this within the policy?
- It's imperative that the policy highlights that a physical break is not always practical, especially for cared for persons with certain characteristics. To 'have the load lightened' can be just as important, this could be a service which provides advocacy/legal support – anything that gives carers more capacity to cope and more headspace. (In the longer term this is more cost effective too!)
- Sense that the policy currently doesn't express the creativity and/or variety of short break options. While it is the role of the SSBS to spell out the detail, the policy needs an explanatory note to express that a short break can vary from individual to individual and from an hour-long activity to a week away.
- Carers who live elsewhere but care for a person in Edinburgh are also entitled to access an Adult Carer Support Plan locally, not sure if that is said.
- There was discussion about the impact of Covid19 and Shielding Groups which unpaid carers were directly linked too and the increase in carer exhaustion and anxiety in relation to this. While this is a policy document should it have a statement to reflect an acknowledgement (underpinned by report evidence) of the current situation?
- Carers who have no recourse to public funds people with no recourse to public funds - where do they fall within this policy? Are they included and if they are not then is there something else which addresses this – could there be a link to this?
- There is not enough with regard to Equalities section. Nor addressing the impact or poverty on all aspects of life, including having to give up work.

## **We will:**

- ✓ Change section 2.3 to clearly highlight who is in scope of the policy and who is not.
- ✓ Define the term carer more clearly within both the opening statement and definition.
- ✓ Remove the section which highlights the short break hub for people with Learning Disabilities from the policy with a view to including within the procedure.
- ✓ Re-consider the opening statement and overall purpose of the policy to greater reflect multiple caring roles.
- ✓ Include the purpose of a break from caring should sustain carer's ability to continue in their caring role.
- ✓ Add hospital within transition's section and provide further guidance within the procedure.
- ✓ Ensure any impacts from protected characteristics and socioeconomic factors are included within the principles of the policy, including giving up work and reduced household income.
- ✓ Include Carers living out of authority but caring for a person in Edinburgh are also entitled to access an Adult Carer Support Plan locally.
- ✓ Ensure poverty and inability to work is highlighted within the policy.

## **Feedback which will inform the development of the Procedure or updated Short Break Services Statement:**

- The purpose of policy often lacks clarity – as professionals we don't have a clear guidance of policy. There is a lot of work needed to take in all the different provisions of support. Having this policy will help to bring everything together. Having a clear underpinning of values will help to bring together different aspects of the services across the city.
- It is important to acknowledge the proportion of what the third sector provide to health & social care services.
- A once in a lifetime holiday doesn't always help you cope in the long term.
- We need something that is sustainable and reliable.
- Replacement care is not always the short break that Carers want.
- The Policy is a good step forward, but will it be implemented.
- Assessment process is complex and time consuming. The threat of it being removed is always in back of your mind.
- Carers cannot survive with just one short break a year.
- It's all very well saying choice empowers us as carers. It feels like the onus is on us as carers to help ourselves. I am overwhelmed most of the time and I do not have the time or head space to be 'creative or imaginative'. 'Too much information fired at me is equally exhausting.
- Yes, carers need to look after self to keep being able to care. Is this just the cheapest way to provide care.
- The policy is only as good as delivery – there needs to be a tangible next step.
- What is the appeal process if someone was not granted a short break fund or service?

- Multiple and complex caring roles can be progressive or multiple and complex from the start. This can include caring for a person with multiple conditions and/or caring for more than one person with different conditions. Getting a short break for these carers is a survival tool. A number need building based cover for their cared for person, for safety, high care levels and consistency, buildings are not all bad! (my person needs building based care and that is when I get a proper break because I know he is being safely managed and he needs to be safely managed! I couldn't relax if he was anywhere else).
- A flow chart with website links would help carers to find the sections that are most applicable to them.
- Issue regarding people not identifying as a Carer.
- 3 Conversations – When a carer needs a break, it needs to be discussed as part of Conversation 1, preventative approach, not waiting until Conversation 3 when the Carer and family may be in crisis. Eligibility Criteria on page 5 would suggest something else and that concerned the group).
- The group had to ask clarification on what some sections meant – for example in part 4.8 and Eligibility statement. Albeit is noted that is clear if you work in the arena. However, will workers to whom it will be rolled out to understand the meaning. This document should be accessible to staff and carers, perhaps in a booklet form.
- Section 4.8.4 – Adult Carer Support Plan's needs to be an ongoing thing for carers, they need to be able to come back to whoever did the plan as transitions and changes change their need for a break.
- How this policy relates to Adult Carer Support Plans and short break discussions are incorporated into the plans needs to be thought through further.
- Questions over capacity were raised, to do Adult Carer Support Plan's and to review them even on an annual basis is this a genuine possibility? And will that be the original person, place that did the initial plan? Has demand and capacity been matched?
- We need to know what the need is in order to be identifying the resources required to meet it in relation to Adult Carer Support Plan's and Short Breaks. We need to be clear on what is deliverable.
- How can we make the Short Break Services Statement more accessible? Can it explain what is a short break and all the diverse options available but in a more accessible, easy read fashion? QR codes, links embedded throughout so it is easy to get to providers websites, latest info etc. Would need to be updated regularly to remain meaningful.
- Strong partnership work between agencies is essential.



**Feedback which will be shared with The Carers Strategic Partnership Group and Commissioning Colleagues:**

- Adult Carer Support Plan's are not being used to full potential.
- There is still a high level of untapped need within the city – carers who are not accessing any support.
- It is important to inform carers groups across the city who have not been involved in the process – how will the policy be communicated to groups across the city?
- Provision of care is often provided by the third sector. When there is inconsistent funding, this means inconsistent provision (e.g., Carers council). A steady policy can only be provided if all of those support networks are in place. Continuity is needed – relying on something and then having it taken away – 'you lose trust'.
- Will the Third sector receive long term funding? It is unacceptable that services are withdrawn due to funding issues.
- There is a lack of options available in replacement care – due to wider external factors.
- the information needs to go to those in Universities for up and coming workers.
- There is not enough with regard to Equalities section. Nor addressing the impact or poverty on all aspects of life, including having to give up work.

**Next Steps:**

- ✓ An Integrated Impact Assessment was completed in 2022. This will be reviewed with further actions included to reflect the feedback from the focus groups. The IIA will then be published.
- ✓ A final draft of the policy will now be completed and shared with appropriate Senior Managers for agreement.
- ✓ On agreement, a procedure will be created to support effective implementation on the policy.
- ✓ The Short Break Services Statement will be reviewed and updated.

As highlighted above the feedback provided will inform these future developments. Once again, the Partnership would like to thank everyone who has contributed to providing this feedback and sharing their own experiences.

If there is any further feedback you would like to share, you can do so by emailing: [r.smith@edinburgh.gov.uk](mailto:r.smith@edinburgh.gov.uk) and [emma.pemberton@edinburgh.gov.uk](mailto:emma.pemberton@edinburgh.gov.uk)



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