

STRATEGY DEVELOPMENT GROUP

# Developing the next strategy to support Unpaid Carers in Moray



Supporting Unpaid Carers

Engagement report - March 2022



### Contents

1. Thank you .....	3
2. Introduction .....	3
3. Summary of emerging themes and next steps .....	4
4. Background .....	5
5. Methodology .....	6
6. Discussions at carer focus groups .....	9
7. Carers questionnaire findings .....	12
8. Emerging strategy themes .....	23
9. Get involved in the next part of developing the strategy .....	25
10. Lived Experience Advisory Forum – come and join us .....	26

**This report is available on our website –**  
**<https://hscmoray.co.uk/engagement>**

If you would like a copy of this document in an alternative format, have any questions about the information contained in the report or would like to be involved in the work being taken forward to develop the next strategy for Unpaid Carers in Moray, please contact us.

**Involvement Officer  
Health & Social Care Moray  
9C Southfield Drive  
Elgin IV30 6GR**

**[involvement@moray.gov.uk](mailto:involvement@moray.gov.uk)**

**[www.hscmoray.co.uk](http://www.hscmoray.co.uk)**

### 1. Thank you

The Strategy Development Group would like to thank all participants who gave their time to share their lived experience as an unpaid carer in Moray during the first phase of our engagement.

We recognise that we only reached a small proportion of the growing number of people who provide or have provided care to a family member, friend or neighbour, but hope those we were able to engage with feel this report presents an accurate reflection of the experiences and issues they shared.

Caring at any time is a challenge. It was evident from what we were told that the past two years have been

incredibly hard for carers - impacting on their physical and mental health and wellbeing, social and financial inclusion and their ability to participate in education and employment.

The Covid-19 pandemic has further highlighted the many and increasing demands faced by unpaid carers and reinforced how essential they are not just in terms of the support they provide to the people they care for, but collectively as a vital partner within the health and social care system.

It is more important than ever that carers are recognised and valued, and that the right support is in place to help them throughout their journey as a carer.

### 2. Introduction

The Moray Integration Joint Board has delegated responsibility for community-based health and social care services. This includes support for unpaid carers.

Services are provided directly through Health & Social Care Moray – a partnership of Moray Council and NHS Grampian – and with the Third and Independent Sectors.

Both the Board and Health & Social Care Moray are committed to improving the ways they actively involve people who have lived experience in the planning, design and delivery of services.

The existing strategies for adult carers and young carers in Moray are to be

updated by a single strategy which will take a whole life approach.

To ensure the strategy reflects and responds to local needs and aspirations, it is important carers of all ages are involved in its development.

This report presents the findings from the first phase of engagement to discover more about the experiences of unpaid carers in Moray and what matters to them.

The engagement was carried out from August - October 2021 by the Strategy Development Group which includes the unpaid carer representative on the Moray Integration Joint Board, officers from Health & Social Care Moray and from Quarriers Carer Support Service (Moray).

### **3. Summary of emerging themes and next steps**

We analysed our notes from the discussion groups held with carers and the responses to the survey to identify five top level themes for the new strategy to deliver on. These are:

1. Carers are supported by carer-aware communities
2. Carers have access to information, advice and support
3. Carers are supported to have a life alongside caring
4. Carers are valued and empowered
5. Carers are supported in education and the workplace

During April, we will carry out further engagement to check we have heard and understood what is important to carers. We will discuss whether these themes are the right ones for Moray and if there are any other themes that should be included in the strategy. We can then begin to develop actions for improvement.

Details of how to get involved in this next stage are on Page 25.

We will continue to develop the next strategy with unpaid carers in Moray and expect to have the first draft of the document ready by summer. There will be a period of consultation before the strategy is finalised and presented to the Moray Integration Board for approval to deliver what carers have said will make a difference to their health and wellbeing.

## Developing the next strategy to support Unpaid Carers in Moray

The following table summarised how the proposed themes for Moray would link to the existing national priorities and policy drivers.

Proposed strategy themes for Moray	Carers are supported by carer-aware communities	Carers have access to information, advice and support	Carers are supported to have a life alongside caring	Carers are valued and empowered	Carers are supported in education and the workplace
National priorities and policy drivers					
National health and wellbeing outcomes	<p>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.</p> <ul style="list-style-type: none"> <li>➤ I feel I get the support I need to keep on with my caring role for as long as I want to do that</li> <li>➤ I am happy with the quality of my life and the life of the person I care for</li> <li>➤ I can look after my own health and wellbeing</li> </ul>				
Carers Act 2016	Am I a carer?	Carer Support Plan / Statement	Support as a Carer	Involvement in services	Hospital discharge
Carers have the right to:	Access a local information and advice service	Request an Adult Carer Support Plan or Young Carer Statement	Access support to meet their eligible needs	Be consulted on services for them and the person they are caring for	Be included in the hospital discharge of the person they are caring for.
Equal Partners in Care	Carers are identified	Carers are supported and empowered to manage their caring role	Carers are enabled to have a life outside of caring	Carers are fully engaged in the planning and shaping of services	Carers are free from disadvantage and discrimination related to their caring role
Core principles					

- [National Health and Wellbeing Outcomes](#)
- [Carers Act 2016](#)
- [Equal Partners in Care](#)

### 4. Background

The actual number of unpaid carers living in Scotland is not known but it was estimated that there were around 700,000 to 800,000 prior to March 2020. Evidence suggests that number has now grown to over 1,000,000, with many people becoming a carer over the past two years of the Covid-19 pandemic, while others saw an increase in their caring commitments.

There are growing numbers of older carers and carers who are looking after more than one person. Nearly half of carers have long-term conditions themselves. The time individuals spend caring is also increasing and many carers are looking after people with complex needs.

It should never be assumed that all unpaid carers are fully able or willing to take on or continue in a caring role.

For many, supporting families, friends and neighbours can provide a sense of well-being. For others, providing support or balancing care alongside other commitments such as family life, employment and education, can have a major impact on every aspect of life.

Not all may need formal support from statutory services to assist them to manage the demands of the role but carers' legislative rights are enshrined by the Carers (Scotland) Act 2016. The Act recognises that preventative support at an early stage can reduce the risk of carers coming to crisis and help them to continue to manage independently.

The development of a new strategy for unpaid carers in Moray will be an opportunity to improve recognition of unpaid carers of all ages in Moray and ensure their rights are upheld.

The three year plan will need to respond to national strategic planning and policy developments for carers and determine local priorities which take into account the impact of the Covid-19 pandemic on unpaid carers and the opportunities identified by carers themselves to improve services, experiences and health and wellbeing outcomes.

### 5. Methodology

From August to October 2021, the Strategy Development Group carried out engagement work to inform the next unpaid carers' strategy.

Engagement consisted of initial focus group discussions followed by a questionnaire to better understand the impact the current situation and the caring role has had on carers in Moray, including understanding what has worked well and what could be improved in the future.

## Developing the next strategy to support Unpaid Carers in Moray

The focus groups were held in August 2021 and promoted by Quarriers to carers registered with the organisation. They took place virtually using the Zoom platform.

The survey launched on 01 October 2021 and remained open for a four-week period. It was hosted online using the Survey Monkey platform and printed copies were made available on request. It was promoted by partners via newsletters and social media using a number of networks and emailing lists for wider cascade, including circulation across Health & Social Care Moray, NHS Grampian, Third Sector Organisations and service providers.

### Who we heard from

Eight focus group discussion sessions were conducted to provide carers with an opportunity to come together to share their experiences. These were facilitated by members of the strategy development group, promoted through Quarriers and took place virtually due to the ongoing pandemic. The table below gives a breakdown of the sessions held and the number of carers participating (where recorded).

#### Adults

Date	10.08.21	12.08.21	18.08.21	24.08.21	31.08.21
Group	Parent carers	Older carers	Working carers	Rural carers	Open
Numbers	2	8	NA	3	3

#### Young carers

Date	06.09.21	08.09.21	13.10.21
Group	Speyside High School	Lossiemouth High School	Quarriers
Numbers	4	NA	NA

Following the focus groups discussions, the opportunity was taken to expand the question set for use in the questionnaire.

The questionnaire was completed by 181 people. Almost all (98%) told us they were currently in a caring role or had been in the past. The remainder were people who support unpaid carers.

85% of people identified themselves as female, and 15% identified as male. No person completed any other options.

Most carers completing the survey were aged between 46-59 (40%), 60-74 (29%) and 30-45 (27%). The survey had a limited response from carers under the age of 30 or the 75s and over.

Almost half (46%) were caring for more than 50 hours a week.

96 carers said they were providing care and support to one or more adults aged 65+, 57 were caring for an adult aged 18-64 and 48 were caring for a child or young person.

Carers were caring for people with a range of conditions. The survey had multiple options for respondents and many respondents indicated that more than one applied. The reported conditions in order of frequency were: long term condition (75), physical disability (58), frailty (51), neurological condition (43), learning disability (38), autistic spectrum disorder (35), mental health (32), dementia (24), life limiting illness (19), sensory loss or impairment (18), substance use (5).

A quarter of carers were working full-time with 23% being retired. 21% worked part-time with the same unable to work because of their caring role. 11% were unable to work due to their own health issues.

Half of respondents indicated they themselves had a health condition or disability.



## 6. Discussions at carer focus groups

We asked focus group participants about the things that helped them continue in their caring role and what mattered most to them in terms of their own wellbeing.

### Question - What helps you keep going in your caring role?

Adult carers	Young carers
<ul style="list-style-type: none"> <li>• No alternative</li> <li>• Family members, friends and community groups play a supportive role</li> <li>• Access to support from GP, counselling, Shared Lives</li> <li>• Organisations switched to providing online digital support during the pandemic</li> </ul>	<ul style="list-style-type: none"> <li>• Seeing friends</li> <li>• Support from extended family</li> <li>• Support worker from Quarriers</li> <li>• Support within school</li> <li>• Support for the person cared for</li> <li>• Having a break and time to follow personal interests</li> <li>• Pets</li> </ul>

### Question - Thinking about your own wellbeing, rather than the person you care for, what is most important to you?

Adult carers	Young carers
<ul style="list-style-type: none"> <li>• Being in employment</li> <li>• Protected time</li> <li>• Support to have a break</li> <li>• Being aware of available support</li> <li>• Being able to access support easily and at the right time</li> <li>• Activities such as walking</li> <li>• Being able to socialise</li> <li>• Access to digital technology to keep in contact with others</li> <li>• Access to health services</li> </ul>	<ul style="list-style-type: none"> <li>• Being respected</li> <li>• Professionals sticking with you</li> <li>• Teachers understanding the impact of the caring role</li> <li>• Not feeling different</li> <li>• Having time to myself</li> <li>• Spending time with friends in person or via social media</li> <li>• Having someone to talk to</li> <li>• Music, going for a walk, journaling</li> <li>• Being able to look forward for the future</li> <li>• LGBTQ group</li> </ul>

We also asked focus group participants to share their views about the challenges they experience and what support would make a difference to help them to overcome the challenges. The table below provides a summary of the main points which were highlighted.

### Question - What challenges have you experienced as an unpaid carer?

#### Adults

- Having no choice but to continue in the caring role as an alternative is not available
- Reluctance to ask for help
- Not being heard or listened to
- Lack of family support
- Increased pressures and demands as a result of the pandemic
- Loss of social care support due to Covid restrictions and unable to source alternative support
- Negative impact on mental health and wellbeing with carers experiencing issues of anxiety, stress and feeling overwhelmed
- Lack of emotional support
- Feelings of isolation
- No protected time to have a break
- Lack of opportunities during school holidays for children with additional support needs
- Being unable to access any formal social care support
- Difficulty in navigating the complex social care system and assessment process
- Long waiting times for social care support
- Poor communication from social care or being able to contact someone
- Social care feels like a battle
- Carers not being respected as equal partners and not being included in care and support planning
- Lack of continuity in the staff supporting the cared for causes anxiety
- Lack of services for certain age groups or people with certain conditions
- Lack of capacity in services
- Poor transition planning for young people moving into adult services
- Dealing with immediate challenges can make planning for the future impossible
- Financial challenges
- Completing forms
- Lack of help with practical tasks
- Balancing work and caring responsibilities
- Inability to take up employment
- Timing of social care services not matching working day
- Decision being made on the basis of budget rather than needs
- Lack of consistency in how SDS is used by people

#### Young carers

- The impact on family life of the condition of the cared
- The impact on studying, homework and school attendance of the caring role
- Stress
- Lack of recognition and understanding of the caring role from the school
- Not being in contact with other young carers
- No knowing where to go for information
- Not knowing where to go for support
- Not having a break, time to myself or time to follow my own interests

### Question - What would help you overcome these challenges and help you in your caring role?

#### Adults

- Greater **awareness** of carers and the impact of the caring role
- Improved **identification** and **recognition** of carers as being expert in the needs of the cared for
- Greater **involvement** of carers in support planning
- Improved understanding of the impact of the caring role on someone's **health and wellbeing** with professionals responding appropriately
- More **support** to those who take on a caring role following a sudden change in circumstances
- Improved access to information
- A simpler **social care system** to make it easier to understand and navigate
- Improved **integration** of services
- More consistent **communication** and recording of information by professionals
- Improved provision of support for the cared for which is personalised and flexible to meet changing needs
- Greater provision of **short breaks** to increase choices available including planned and emergency breaks, accommodated and non-accommodated respite
- Improved access to **mental health support**, including counselling, to increase resilience
- Greater **consistency** in support staff for the cared for
- More **holiday programmes** for children
- Increased **funding** for carer support services
- More opportunities for **peer support**, support to gain confidence to join in activities and attend meetings
- Rapid access to **crisis** support
- Improved **availability** of social workers
- Increased **assurance** checks that services are meeting needs and improving outcomes
- Improved outcomes as a result of the **carers assessment**
- Improved **support** for young carers/sibling carers in education

#### Young carers

- Raised **awareness** of young carers
- Improved support for young carers within **schools** including support for homework
- Opportunity to **meet other young carers**
- Easy access to **carer information and support**
- Easy access to **health condition information/training**
- Being **included** in care, support and treatment discussions
- More opportunities to have a **break**, time to myself or time to follow my own interests

## 7. Carers questionnaire findings

The following is a summary of the general answers received to the questionnaire. Some individual responses are shared to highlight key points.

### A. What or who helps you in your caring role?

Caring responsibilities can have a major impact on every aspect of a carer's life and additional support is needed to manage the demands of the role. We asked carers what or who they found supportive.

In their free text responses, many carers told us they had no help and were trying to cope as best they could with their situation and the fluctuating/increasing needs of the person they cared for.

*"Nobody as struggling to get any help."*

*"I have looked after my wife for 7 years, never had a break, in fact I've never been away from her side in all that time."*

*"My wife's greatest pleasure is her garden but that is now not possible."*

Some carers were able to turn to supportive family, friends and neighbours for practical and emotional help, but that often depending on the other person's own work or family commitments and was limited to certain times or tasks.

Many carers were trying to balance their caring role with other responsibilities. Social care services provided limited support for some.

*"Recent health decline has meant that I need support to care in the mornings as although I am working at home three days a week I am 'working' and therefore cannot be available to deliver care simultaneously."*

*"Used to have a care company come in but they weren't any good & let us down badly so I changed job so now I work evenings so that my son, daughter & parents can be there when I work to ensure he takes his meds & that he eats."*

*"After a stay in hospital my husband now has a carer in once a day but only for a short time. This is great as someone is helping him shower and dress and make sure he is ok."*

*"My partner has a care plan and he receives a morning visit 7 days a week from the care worker to prepare him for the day. I do the rest as I work from home."*

*"Carers provided by an SDS package - without them what has been achieved for my wife would not have been possible."*

A number of carers highlighted the assistance they receive from Quarriers which is commissioned by Health & Social Care Moray and Moray Council to provide services to adult and young carers. The organisation also attracts funding from a range of sources for additional carer activities.

*“Quarriers newsletters are very helpful in providing information and pointing me to activities/groups/learning opportunities I might want to join.”*

*“Counselling service arranged by Quarriers.”*

### **B. What challenges do you experience in your role as a carer?**

Carers experienced many struggles before the pandemic and have faced new and additional challenges and pressures as a result of lockdowns, loss of informal support and disruption to services.

Carers own health issues, as well as the health condition of the person they cared for, has been a concern. The demands of the role impacted on both physical health and mental wellbeing. They spoke of the stress they were under, their lack of sleep and tiredness, worry, feelings of guilt and isolation which had made it more challenging to cope in the caring role.

The inability to have a break was the biggest challenge for most carers and had a negative impact on many aspects of their life including relationships.

*“Providing 24 hour care without any respite provision. Physical and mental exhaustion.”*

*“Loss of a wife and partner. Physically having to do everything to keep the house going.”*

*“The constant asking of the same questions all day and every day. Not having any family close by to give me a break. Having to see to everything now - banking, insurances, all household repairs etc.”*

*“Not knowing when my son will have a meltdown or how violent it will be.”*

*“My role as a carer is very physically and emotionally demanding on me. I too have disabilities so my physical and mental health is really suffering... I feel very lonely and isolated and don't have much of a life outside of my caring role.”*

*“The relentless nature of caring for someone in the advanced stages of M/S.”*

*“If he doesn't sleep at night then nor do I but I still have to work the following day.”*

*“Loss of freedom to get out & about, loneliness at times.”*

*“Feeling that all I can offer is inadequate for my elderly mother who lives alone and gets lonely. I feel guilt as my time is limited.”*

There were many comments from carers who had experienced the loss of support networks and suspension of services for the cared for in response to the pandemic.

*“Covid has affected the person I care for due to being isolated from friends which has led to them feeling anxious.”*

Carers reported a lack of social care support or barriers to accessing the system such as poor communication from social care and bureaucracy. They also highlighted issues with the capacity and quality of current care services.

*“Red tape when trying to make life easier for my Mum.”*

*“Lack of support and communication from social care.”*

*“Health, Education and Social Work have no real understanding of my child's condition. This is a problem because suggested supports are almost always counterproductive.”*

*“Not enough support from services. Phoning and phoning for my call to be answered weeks later. Chasing medications.”*

*“Losing a good / flexible care package as no longer allowed to use self-employed carers. Hopeless care company for personal care, who are currently unable to meet my husband's care needs.”*

*“Not being involved in decision making.”*

*“From a service provider perspective, when they do not come to assist the user, I ended up doing the morning routine. The lack of reliability especially if you work can be stressful.”*

*“The length of time it takes to navigate through services to get an outcome.”*

Difficulties accessing health support were also commented on.

*“Getting mum seen by a doctor before it becomes a crisis situation has been very difficult the last couple of years due to covid.”*

*“Hospital appointments that coincide with my work hours. Access to the GP and refusal of outside care.”*

Others spoke of the pressures of their financial situation and in trying to secure or maintain employment.

*“...uncertainty about future finance for my son and myself.”*

*“Universal Credit covers my mortgage and nothing else: no bills, food, transportation, etc. My energy is limited so although I'm looking for part-time work, I am very concerned about being able to work AND continue caring for my child.”*

*“It's hard not being able to get a break. It's also frustrating not being able to work due to being an unpaid carer and having to rely on benefits.”*

*“Can't find work around caring & can't join in a lot of things as no respite e.g. no day care available after 3/3.30.”*

*“Not being able to take on addition job to earn extra income due to caring for my mum.”*

### C. What would support you to look after your own health and wellbeing?

There is an increasing focus on ensuring a whole-system approach to health and social care which focusses on keeping people well by anticipating health needs,

preventing illness, and reducing the impacts of poor health. This will be achieved in part by promoting positive health and wellbeing with and for all citizens, including self-care and self-management in everyday life.

Carers expressed difficulty, however, in prioritising their own needs above those of the person they support with many indicating they *“don’t have time to be ill”* or that they *“forget about myself until I have no choice but to see to health issues.”*

In response to a question on what would help carers maintain and improve their own health and wellbeing, most mentioned the importance of time away from the caring role in order to have a break, with suitable respite care to relieve them of their responsibilities and commitments so they could rest and recharge, or do something solely for themselves.

*“Time for me.”*

*“Having a few hours to myself – a whole day now and again would be bliss.”*

*“Periods of residential respite care are essential to maintain my sanity.”*

*“Care for my daughter while I took a break.”*

*“Being able to relax and know that they had support without me.”*

*“A befriending service would be a big help as I would know my mum had some company other than me.”*

Having someone to talk to and feeling listened to and understood were also mentioned.

*“A listening ear, support from peers.”*

*“A mentor.”*

*“Availability of counselling.”*

*“More understanding of the effect of daily looking after someone with mental health issues who is also on the spectrum.”*

Carers reported that their stress and worry would be reduced if the social care system was easier to navigate and if they were able to access - in a timely manner - the flexible and personalised support they needed or that the person they cared for required. They also called for better access to information on available support and high quality and appropriately resourced services which could be relied on.

*“If there was a professional, say a social worker, assigned to make contact to see if any help is required & they could assist in getting things in place. This takes the pressure off working through the paperwork etc.”*

*“For care assessments and self-directed support (SDS) budgets to be agreed in a timely manner. For SDS/support budgets to be used creatively as intended to enable personalised outcomes, rather than what social work deems as outcomes.”*



*“Having ready access to carers to supplement the care I provide. I know how stretched care provision is and I already feel guilt for needing to ask for help. So if help was easily available when I do feel able to request it then that would help.”*

*“More freedom to choose the respite that suits my son and myself. The spirit of SDS is not allowed in Moray.”*

*“Better care provision, carers being trained to meet my husband's needs. Continuity of care so I don't have to worry about this.”*

*“Having the knowledge to know that I could call on the care team at short notice to provide more care in an emergency if I should become unwell and to know my parents can stay together at all times if possible.”*

*“We need the peace of mind that the person looked after will be supervised, otherwise you go out but your mind is not relaxed.”*

*“Being able to readily access information, services and resources and being able to do so timeously.”*

For some, practical support with household tasks would make a difference, as would the peace of mind of having financial security.

*“Not having to worry about the day to day stuff like housework quite so much.”*

*“Physical help with the house.”*

*“Better benefits for carers.”*

*“Discounts towards something for my health and wellbeing or money towards it so I can have a break.”*

*“To be able to get carers allowance so that some money is available for joining a club.”*

*“Not needing to work so I could just care for them full time without juggling.”*

### **D. What would help you to have a life alongside your caring role?**

The strategy will aim to address how resources can be used effectively to support carers to have fulfilling lives alongside caring. Respondents were asked what would help them.

Short break options would, carers said, provide the opportunity to have time for themselves. Many currently feel too exhausted to make the most of any time to themselves and highlighted the need for regular respite. Others spoke about having lost their support as a result of the pandemic or because the needs of the cared for had changed.

They reflected that flexible options were often not available due to a lack of staff resource. It was important to carers that they felt listened to by professionals as to what would benefit them and the person they cared for.



Parent carers called for improved support through transition from child to adult services and for children with additional support needs.

*“To have a bank of respite carers, that are assigned based on locality, experience and areas of expertise.”*

*“Respite care so I know dad is safe and looked after if I want to have a night out or go away with my family on holiday.”*

*“If there was another person to share the responsibility of looking after my mother, but I know that isn't possible at the moment.”*

*“Time out for myself to pursue hobbies whilst my partner was cared for in my absence. The relentless nature of caring is exhausting.”*

*“Definitely something available in the later part of the afternoon (perhaps into teatime) as this restricts so much.”*

*“More respite, more opportunities to have a little time to myself as I have my son 24/7. This would allow me to be able to work on my mental health, recharge my batteries and try to get my friendships back.”*

*“To take away the guilt of leaving her with nobody else to keep her company, she gets lonely.”*

Some form of recognition in the form of discounts or rewards was mentioned as was the suggestion that unpaid carers should be paid.

*“Some recognition, monetary contribution or a thank you in some other way, perhaps carers card to give money off things when shopping.”*

*“Discount or money towards something.”*

*“To be paid according to the hours of caring I do.”*

### **E. What changes would make the biggest positive difference to you as a carer?**

In the survey, respondents were invited to share suggestions and ideas on what would be useful to them in their caring role and what would make the biggest difference.

Many reflected on a wish for better health for the person they care for or for themselves. Respondents said they would welcome the chance to share the caring role with others in their family rather than the responsibility always falling to them.

They called for more community activities suitable for the person they care for to attend to reduce social isolation. Information on what is available needs to be easy to access.

Carers want to be recognised and valued for what they do.

*“Recognition that unpaid caring is actually a job in its own right. I had to stay at home, as do thousands of other unpaid carers, as my daughter needed stability... holding down a job was impossible.”*

*“Being able to reduce my working hours to enable me to spend quality time with the person I care for without forfeiting my own future financial security.”*

The provision of high quality respite care so the carer could feel confident taking a short break, knowing that the needs of the cared for were being met, was again highlighted as a priority, along with improved support from health professionals – including a dedicated point of contact and timely access to the care and support needed.

*“Time away from caring role, a listening ear, support from peers, appropriate support from services.”*

*“By treating clients with the care and respect they deserve. They don’t deserve to be messed about.”*

*“Available care - less formal arrangements to allow for spontaneity.”*

*“Keep the person I care for happy.”*

Having suitable housing was also mentioned by carers.

### F. Carers Rights

The Carers (Scotland) Act 2016 extends and enhances the rights of carers. The aim is to better support carers on a more consistent basis so that they can continue to care, if they so wish, in good health and to have a life alongside caring. In relation to young carers, the intention is similar to that for adult carers but also that young carers should have a childhood similar to their non-carer peers.

The survey sought to establish people’s awareness of their rights as unpaid carers and found that 1 in 2 carers were not fully aware of their rights.

Carers (Scotland) Act 2016	Yes I know about this	Yes I had heard about this but I'm not sure what it means	No I have not heard of this
Carers have the right to receive information and advice, including information about their rights as a carer.	39%	26%	35%
Carers have the right to access an Adult Carer Support Plan if they are an adult or a Young Carer Statement if they are under the age of 18.	44%	14%	42%
Carers have the right to be involved in the assessment of their own needs for support.	40%	19%	40%
Carers have the right to access support if their needs meet the local eligibility criteria for carers.	32%	22%	46%
Carers have the right to have their views taken into account when local authorities are assessing the needs of the person that they are caring for.	40%	17%	43%
Carers have the right to be involved in the hospital discharge planning of the person(s) that they are caring for, or plan to care for.	46%	15%	40%
Carers have the right to be involved in the planning of any carers' services that local authorities and health boards provide.	38%	14%	48%

### G. What carer support services have you found useful?

Health & Social Care Moray and Moray Council contract with organisations to offer practical support, advice and information to carers who were asked what worked well for them in terms of dedicated carers support.

Some responded that they did not require a service or didn't have time or the opportunity to access services and a small number were not aware of the available support.

*"Don't know of any, I don't think I class as a carer as don't get Carers Allowance."*

*"None as yet as info out here not as accessible or forthcoming as it should be."*

*"Not accessed these. Where do I get the time?"*

Many had found the information, advice and support offered by Quarriers to be of benefit. The regular communication through newsletters and emails were praised by many.

*“Being able to chat to someone at Quarriers as and when required, money from the government through Quarriers last year to buy something for myself.”*

*“Quarriers is a fantastic help with support and understanding for me.”*

Social work was recognised as being supportive and there was mention of services such as care at home, respite breaks and the Shared Lives service, although carers also underlined a need for improvement in provision. Condition-specific national organisations were found to be helpful in providing support and information.

### **H. What would improve carer support service? What else is needed in Moray?**

The survey was an opportunity to listen to ideas for improvement and what carers had to say about gaps in service provision.

The need for funding to maintain and extend provision of support for carers was highlighted, including flexible support out with working hours and via digital platforms. Carers said they need to be made aware - through advertising and the provision of information and advice – of what support is available and their rights under legislation, and be supported to have their voice heard. This included involvement in hospital discharge.

*“Carer support services to have more funding, more staff, appropriate buildings to provide essential support to unpaid carers, scope to provide the support carers want not what the LA think they should want.”*

*“More services required, more information specifically regarding legislation and new policies.”*

*“Access to legal, medical and financial advice.”*

*“More money to Quarriers to enable them to do nice things for carers.”*

*“Quarriers does good things, but sometimes they are a one-off. Things like the class for parents of children of additional needs don't seem to be repeated but it was a life-saver. Please repeat things that work!”*

*“Strong advocacy service for carers.”*

Support for carers mental health and wellbeing would be welcomed, as would development of carer friendly communities where there is greater understanding of the caring role and its impact on people.

Although the question asked about support services for carers, many answered on the need for services for the cared for. More respite options and the return of services which had been suspended in response to the Covid-19 pandemic were

called for. Carers in rural locations spoke about the lack of services, support and activities in their communities.

*“More day services to allow the individual access to activities.”*

*“More services directed for young people with complex needs.”*

*“In effect something like a ‘baby sitter’ who can be available to stay overnight occasionally.”*

*“Support services that can provide emergency support easier without social work referral which is time consuming and does not meet needs of emergency care. More support services and companies to allow carers to access paid carers. There are so few healthcare organisations and providers in Moray it makes it nearly impossible to even have someone come in for a few hours a week.”*

*“Activities or a hub for children with disabilities no matter if physical or mental. Also help for their siblings too.”*

*“Drop in centre for difficult days.”*

*“More holistic approach to care needs, listen to what people want.”*

*“Respite locations and an understanding of what is really needed by parents of young adults who don't want to put them into care.”*

*“Support for carers not having to wait for approval from Social Services as this seems to be a big hold point for the majority of the support we need.”*

### **I. If you were able to take a break from your caring role, what would a break look like for you?**

Access to regular and meaningful breaks from caring is one of the most important factors in carers being able to maintain their own health and wellbeing. The national Independent Review of Adult Social Care has recommended a right to respite for unpaid carers.

Throughout the survey, access to respite came up repeatedly as a priority. Carers told us they had struggled to access breaks that met their needs prior to March 2020 and that the suspension of many respite services during the pandemic had put them under increased strain.

The responses from carers as to what a break would look like for them, underlined the requirement to develop a greater range and more imaginative options for both the supported person and unpaid carers to better meet needs and preferences.

They told us that a break is an opportunity to leave caring responsibilities behind for a time, to have a degree of ‘freedom’ and recharge. This obviously means different things to each carer - from a weekend away with or visiting family and friends, time to spend on an interest or hobby or just to read a book.

Carers need peace of mind that the needs of the cared for are being met in the right way while they are having a break.

*“A day without having to worry about my mum.”*

*“A day out of the house relaxing.”*

*“Catching up on sleep.”*

*“Being sure my husband was safe.”*

*“Time away knowing my mum had someone else to keep her company, not just a random person but someone she grows to know and trust.”*

Many carers felt there was no realistic prospect of them being able to have a break. Their caring role is constant.

*“I cannot. Nobody will do what I have to do. I am stuck, I married for better or worse so I feel guilty having any break without her with me.”*

*“It would be a day where I don't worry if my daughter has woken up too early, can eat without a fight, can get dressed without a fight, not have to panic on her running all the way to school, not having to worry through the day every time my phone rings, what she is going to be like when picked up from school and how she is going to be at home and then bedtime. If I were to take a break all of these things would be here. I have no one to look after my daughter so getting away is not an option.”*

*“I'm crying thinking about this. I have no idea and don't dare think about it.”*

*“No break at all – always on duty.”*

*“I'd worry too much about what would happen if I wasn't there to do it.”*

## 8. Emerging strategy themes

The following five draft themes have been identified from the experiences shared. These will start to inform the priorities for the next strategy. Each priority will contain a number of improvement actions to be achieved over the lifetime of the strategy.

### Themes:

1. Carers are supported by carer-aware communities	
Where we are now	Where we want to be
Many people who have caring responsibilities do not recognise themselves as carers. This means that they may miss out on support available to them. Carers feel lonely and socially isolated as a result of looking after a loved one.	<ul style="list-style-type: none"> <li>• There is improved identification, recognition and understanding of carers by those working in health and social care, by public services and by communities.</li> <li>• Communities are enabled to build their capacity to support carers.</li> </ul>

  

2. Carers have access to information, advice and support	
Where we are now	Where we want to be
Carers are often not aware of the available help and support available to them.	<ul style="list-style-type: none"> <li>• Carers have access to the right information and advice at the right time.</li> <li>• They can access practical, emotional and peer support and activities.</li> </ul>

  

3. Carers are supported to have a life alongside caring	
Where we are now	Where we want to be
Carers are at increased risk of poor physical and mental health and wellbeing because they often put the needs of the person they care for before their own. The pandemic has taken a heavy toll on carers, challenging their ability to sustain relationships without their usual support. A quality break means different things to different people. It is important to carers that it benefits both parties.	<ul style="list-style-type: none"> <li>• Carers are connected to the health and wellbeing services, training and carer support they need to look after their own health and wellbeing, with a greater focus on prevention and crisis support to keep people well and safe from harm.</li> <li>• All carers have the opportunity to take breaks from their caring role to enable them to maintain their own health and wellbeing and have a life alongside caring.</li> </ul>

#### 4. Carers are valued and empowered

Where we are now	Where we want to be
<p>Carers are not recognised as equal partners in care. Carers are frustrated by the current health and social care system which they find difficult to navigate. Communication is poor and decision-making is slow and unclear.</p>	<ul style="list-style-type: none"> <li>• Carers are recognised as being equal, valued and expert and supported to make informed choices about the care they provide.</li> <li>• Carers are aware of and are able to exercise their rights. They have opportunities to engage in service planning, design and delivery.</li> <li>• Carers are able to access the support they need whilst caring and when the caring role comes to an end.</li> </ul>

#### 5. Carers are supported in education and the workplace

Where we are now	Where we want to be
<p>For young carers there is a risk that their caring role could negatively affect their education and opportunities for employment. Caring has a financial impact on carers. Carers have had to give up employment opportunities or reduce their work hours to care, which impacts on their financial wellbeing and increases social isolation.</p>	<ul style="list-style-type: none"> <li>• Carers are free from disadvantage and discrimination related to their caring role.</li> <li>• Carers can supported to build and maintain social connections.</li> <li>• Carers are enabled to learn alongside their caring role through improved support in educational/training settings</li> <li>• Carers are enabled to work alongside their caring role through improved workplaces policies and practices</li> <li>• Carers can access the financial support and assistance they are entitled to.</li> </ul>



## 9. Get involved in the next part of developing the strategy

We welcome all unpaid carers – whether they were involved in the first stage of engagement or not – to work with us to continue developing the future priorities and improvement actions for the strategy.

5 high level themes have been identified from the work so far:

1. Carers are supported by carer-aware communities
2. Carers have access to information, advice and support
3. Carers are supported to have a life alongside caring
4. Carers are valued and empowered
5. Carers are supported in education and the workplace

We now want to ask carers the following questions:

- Are these five themes the right ones for Moray?
- Are there any others which should be included?
- What are the top 3 improvement actions we need to work on under each theme?
- If you suggested any other themes, what are the top 3 improvement actions we need to work on?
- How will we know if the strategy and improvement actions are making a difference?
- Is there anything else we need to consider?

You can get involved in a number of ways.

### Join one of our online discussion sessions

These will be held on the following dates – contact us by email to and we will send you the joining details.

- Monday 18 April – 10.30-11.30am
- Tuesday 19 April – 2-3pm
- Thursday 28 April – 7-8pm

### Go to our online survey

You can use our online survey to answer the questions.

- <https://www.surveymonkey.co.uk/r/MorayUnpaidCarers>



### Send your comments to us

[involvement@moray.gov.uk](mailto:involvement@moray.gov.uk)

Involvement Officer  
Health & Social Care Moray  
9C Southfield Drive  
Elgin IV30 6GR

## 10. Lived Experience Advisory Forum – come and join us

Health & Social Care Moray is supporting people to come together to form a new Unpaid Carer Lived Experience Advisory Forum.

The forum will be a community of people who know what it is like to be a carer and who are want to make a difference to the lives of fellow carers by sharing their lived experience, their views on hot topics and ideas for improvement.

Meetings of the forum will be both in person and on line to give as many carers as possible the opportunity to take part.

The collective voice of the Lived Experience Advisory Forum (LEAF) will help to inform and influence strategic development, service planning and delivery.

It will be chaired by the Unpaid Carer Representative on the Moray Integration Joint Board (MIJB), enabling them to ensure their involvement as a Board member is reflective of the views of a wider range of carers.

Members of the group will also have opportunities to champion carer involvement as equal, expert and valued partners within the governance structures of the MIJB and within Health & Social Care Moray's transformation and improvement programmes.

Anyone interested is asked to contact the Involvement Officer at Health & Social Care Moray who can provide more information.

**Involvement Officer  
Health & Social Care Moray  
9C Southfield Drive  
Elgin IV30 6GR**

**[involvement@moray.gov.uk](mailto:involvement@moray.gov.uk)**

**07970 826897**

**[www.hscmoray.co.uk](http://www.hscmoray.co.uk)**

