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Agenda Item: 13

## **Integration Joint Board**

Date of Meeting: 27 March 2019.

Subject: Carers' Strategy.

## 1. Summary

1.1. This report attaches the final draft of the Carers' Strategy 2019 to 2022, following the recent consultation and engagement process.

## 2. Purpose

- 2.1. To present the final draft of Orkney Health and Care Carers' Strategy 2019 to 2022, along with the associated Action Plan, following the recent consultation and engagement process.
- 2.2. To seek approval to publish the Strategy.

#### 3. Recommendations

The Integration Joint Board is invited to Note:

- 3.1. That the stakeholder consultation is now complete.
- 3.2. The findings of the consultation as detailed in Section 5 below.

#### It is recommended:

3.3. That the Orkney Health and Care Carers' Strategy 2019 to 2022, attached as Appendix 1 to this report, be approved for publication.

## 4. Background

- 4.1. The Carers (Scotland) Act 2016 (the Act) is a key piece of new legislation that promises to 'promote, defend and extend the rights' of adult and young carers across Scotland. The Act commenced on 1 April 2018.
- 4.2. The principle behind the Act is to enhance and extend the rights of adult carers and young carers to improve their individual outcomes whilst adopting a more consistent approach across Scotland. The Act requires to be taken account of when

preparing health and social care services as well as within the context of other social care and health legislation, such as self-directed support.

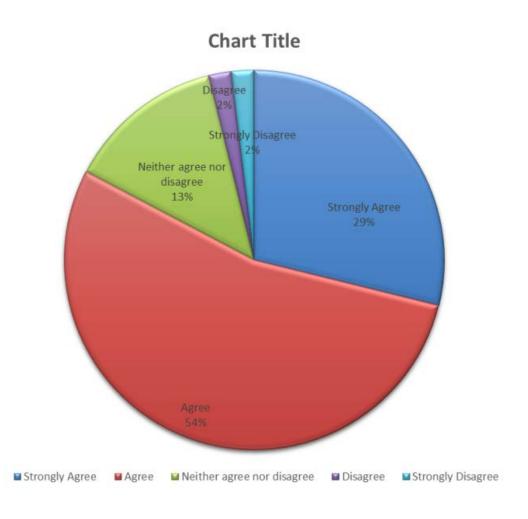
- 4.3. At its meeting held on 27 September 2017, the Integration Joint Board noted inter alia:
- 4.3.1. The passing of the Carers (Scotland) Act 2016 and the new powers and duties placed on local authorities.
- 4.4. Publication of the Regulations and Guidance clarified a requirement of the Act that local authorities and health boards produce and publish a Local Carers' Strategy, on or before 31 March 2019.
- 4.5. At its meeting on 28 November 2018, the Integration Joint Board approved the draft of the Carers' Strategy 2019 to 2022 for stakeholder consultation.

## 5. Consultation Report

- 5.1. The views of all stakeholders were sought to inform and validate the draft Carers' Strategy. Stakeholders included:
- Unpaid Carers.
- Social Workers.
- Home Care Workers.
- Community Occupational Therapists.
- Third sector support agencies.
- Orkney Opinions Group.
- Primary Care Workers (via the Primary Care Newsletter).
- 5.2. The consultation took the form of a survey, with responses sought in writing, via email and via the Smart Survey online platform. Invitations to respond provided either an electronic copy of the draft Carers' Strategy, or a clickable link to the Strategy.
- 5.3. Orkney Health and Care stakeholders were invited to participate, via email, whilst the Orkney Opinions Group also received the survey via email. Colleagues at Voluntary Action Orkney submitted invitations to third sector agencies and, finally, NHS Primary Care Workers were invited to participate in their regular newsletter.
- 5.4. The survey asked the following three questions:
- 5.4.1. Question 1 The Strategy makes 4 key statements:
- Statement 1: I am supported to identify as a carer and am able to access the information I need.
- Statement 2: I am supported as a carer to manage my caring role.
- Statement 3: I am respected, listened to and involved in planning the services and support which both I and the person I care for receive.
- Statement 4: I am supported to have a life alongside caring, if I choose to do so.

- Please tell us if you think that the Statements are focusing on the right things:
- 5.4.2. Question 2. Please tell us if the Statements have missed anything.
- 5.4.3. Question 3. Do you have any further comments or suggestions regarding the Draft Carers' Strategy?
- 5.5. A total of 52 responses were received: 39 via Orkney Opinions, 11 via the Smart Survey platform and 2 via email. There were no paper responses. The survey did not ask the respondents to identify themselves. Those responses received by email were anonymised.
- 5.6. In response to Question 1, all participants responded as follows:

| Strongly Agree.             | 15. |
|-----------------------------|-----|
| Agree.                      | 28. |
| Neither Agree nor Disagree. | 7.  |
| Disagree.                   | 1.  |
| Strongly Disagree.          | 1.  |



5.7. The detailed responses received from each of the participants in response to Questions 2 and 3 are attached as Appendix 2 attached to this report. However, the following is a summary of the issues that became apparent from the responses, together with our response:

| Comment.  | Response.  |
|---|--|
| I am an unpaid carer and receive no support whatsoever.   | The strategy addresses how OHAC and partners will raise awareness of unpaid carers, as well as make them aware of how and where they can seek the support that they need.  |
| How do unpaid carers find out about the support available to them?  | Please see the response above.   |
| Siblings of supported children are negatively affected by the circumstances in the home – should they be acknowledged as young carers, even if they are not delivering the care?                                      | We recognise that this is a significant issue and seek to identify such children and address their support needs through the relevant Children in Need legislation.  |
| The strategy mentions adult carer support from Crossroads; is this not also available to young carers?  | Crossroads do, indeed, provide carer support services for young people. This has been clarified in the strategy.   |
| Vicarious trauma associated with caring for loved ones should be acknowledged and support provided.   | The Carers Act makes explicit provision of support to meet the carer's needs. This strategy will ensure that health and social care professionals are increasingly aware of the needs of carers, both during and after their time as a carer, so that they receive the health and social care services that they need. |
| Will increasing health and social care integration lead to a more formal role of carer assessment amongst health staff?   | All health and social care professionals can make a carer referral. OHAC will continue to raise awareness of unpaid carers, amongst health staff, as well as their role of identifying the support needs of carers and making appropriate referrals.   |
| The provision of respite care should be seen as a service for the carer, as a health preventative measure, rather than the cared-for person and, as such, should be funded by health as well as social care services. | The Integration Joint Board (IJB) is funded by Orkney Islands Council (OIC) and NHS Orkney, with the IJB using the funding to commission services from both the NHS and OIC.   |

| Comment.   | Response.   |
|--|---|
| The strategy needs to say more about how young carers will be supported in the transition to adulthood, especially if they are seeking further education or employment opportunities outwith the county. | If existing adult or young unpaid carers are unable to continue the care support that they currently deliver, an appropriate package of care provision will be discussed and agreed with the cared-for person.  |
| The strategy looks good on paper but may not work well, in practice.   | The Carers' Strategy is our commitment to provide the care and support services that our carers need. The strategy will be constantly reviewed to ensure that the services delivered are consistent with the commitments made in the strategy. Furthermore, the strategy will be fully refreshed and published every three years. |

5.8. A summary of the findings from the consultation, along with the responses to the comments received, has been included in the publication draft of the Carers' Strategy.

## 6. Contribution to quality

Please indicate which of the Council Plan 2018 to 2023 and 2020 vision/quality ambitions are supported in this report adding Yes or No to the relevant area(s):

| Promoting survival: To support our communities.   | Yes. |
|---|------|
| <b>Promoting sustainability</b> : To make sure economic, environmental and social factors are balanced.                     | No.  |
| <b>Promoting equality</b> : To encourage services to provide equal opportunities for everyone.                              | Yes. |
| <b>Working together</b> : To overcome issues more effectively through partnership working.                                  | Yes. |
| Working with communities: To involve community councils, community groups, voluntary groups and individuals in the process. | Yes. |
| <b>Working to provide better services</b> : To improve the planning and delivery of services.                               | Yes. |
| <b>Safe</b> : Avoiding injuries to patients from healthcare that is intended to help them.                                  | No.  |
| Effective: Providing services based on scientific knowledge.  | No.  |
| <b>Efficient</b> : Avoiding waste, including waste of equipment, supplies, ideas, and energy.                               | Yes. |

## 7. Resource implications and identified source of funding

- 7.1. Demand for assessment support planning and the provision of social care services is likely to increase significantly once more people are identified as carers.
- 7.2. An additional £66 million has been allocated by Scottish Government to support additional investment in social care, in recognition of a range of pressures local authorities are facing. These include support for the implementation of the Carers (Scotland) Act 2016, maintaining our joint commitment to the Living Wage (including our agreement to now extend it to cover sleepovers) and an increase in the Free Personal and Nursing Care payments. The Orkney share of this sum equated to an increase of £289,000 baseline budget in respect of all of the commitments mentioned, with no separate specific allocation in respect of the Carers Act.

## 8. Risk and Equality assessment

8.1. The provisions of the Act are considered to contribute to overall risk management across the responsibilities of the health and social care partnership.

## 9. Direction Required

Please indicate if this report requires a direction to be passed to:

| NHS Orkney.                                 | No. |
|---|-----|
| Orkney Islands Council.                     | No. |
| Both NHS Orkney and Orkney Islands Council. | No. |

## 10. Escalation Required

Please indicate if this report requires escalated to:

| NHS Orkney.                                 | No. |
|---|-----|
| Orkney Islands Council.                     | No. |
| Both NHS Orkney and Orkney Islands Council. | No. |

#### 11. Authors

- 11.1. Lynda Bradford, Acting Head of Health and Community Care.
- 11.2. Shaun Hourston-Wells, Project Manager, Orkney Health and Care.

#### 12. Contact details

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- 12.2. Email: <a href="mailto:shaun.hourston-wells@orkney.gov.uk">shaun.hourston-wells@orkney.gov.uk</a>, telephone: 01856873535 extension 2414.

## 13. Supporting documents

- 13.1. Appendix 1: Orkney Health and Care Carers' Strategy 2019 to 2022.
- 13.2. Appendix 2: Carers' Strategy Consultation Full Responses.



## **Carers' Strategy 2019 – 2021**

Orkney Health and Care.



| Version:       | Carers' Strategy 2019-2021. |
|----------------|-----------------------------|
| Lead Manager:  | Sally Shaw.                 |
| Approved by:   | Integration Joint Board.    |
| Date Approved: | TBC.                        |
| Review Date:   | TBC                         |

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| Statement 4: I am supported to have a life alongside caring, if I choose to do so 18  |

#### **Foreword**

We welcome the publication of the Orkney Health and Care Carers' Strategy. The strategy recognises the significant contribution that unpaid carers make to the health and wellbeing of folk in Orkney and the value that we as Orkney Health and Care place on the role that unpaid carers have.

The publication of this strategy is our response to the implementation of the Carers' (Scotland) Act 2016 on 1st April 2018. The Act extends and enhances the rights of unpaid carers. Our strategy seeks to take into account those areas of a carer's life that may be affected by their caring role and identify the provision of a variety of supports in order that they may continue in that role, should they wish to do so. Our aim is that they are enabled to have a life alongside caring.

It is our ambition that the role of unpaid carers is recognised, that their views are heard and used in designing and delivering services, not only for themselves but for those that they care for. We know that undertaking a caring role can often be a demanding and complex task and we hope that this strategy offers opportunities to lighten the load.

We acknowledge the demographic, geographic and financial challenges that we face and we recognise that unpaid carers are key to the sustainability of the health and social care system. Whilst funding is limited we will ensure we target what funding we have to the areas that need it most.

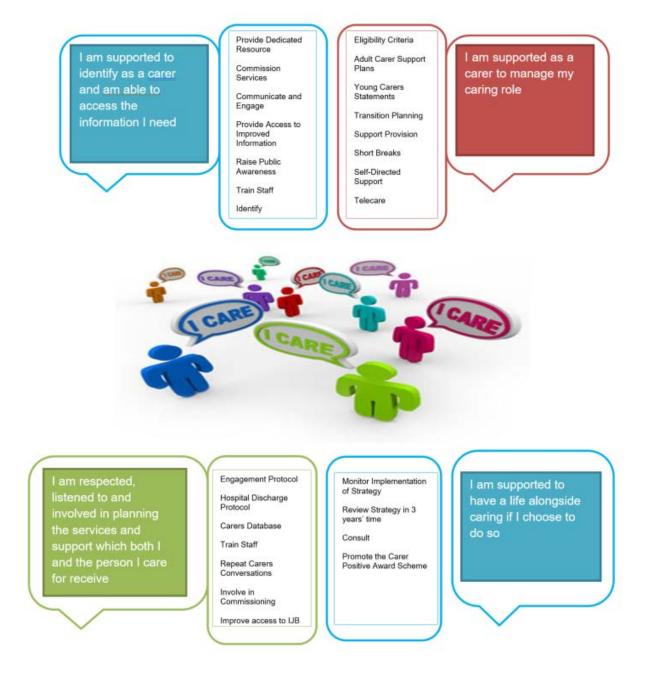
We are committed to ensuring that young carers are seen as children and young people first and foremost, and that any caring responsibilities that they undertake are appropriate and have regard to their age and maturity.

Chair

Integration Joint Board.

## Carers' Strategy at a glance

What we want carers in Orkney to be able to say as a result of this strategy and what we plan to do:



How can this strategy help carers?

| Area of Life.         | Issues.  | How this strategy might help?  |
|-----------------------|--|--|
| Health and Wellbeing. | <ul> <li>Mental health (stress, worry, depression).</li> <li>Sleep and energy levels.</li> <li>Physical health.</li> </ul> | <ul> <li>Respite / short break.</li> <li>Additional service for the cared for person.</li> <li>Support group and activities for carers.</li> </ul> |

|                   |   | Information and advice.   |
|-------------------|---|---|
| Relationships.    | Strained relationships.                               | Counselling.  |
| -                 |   | Respite / short break.  |
|                   |   | <ul> <li>Additional service for the cared for person.</li> </ul>        |
| Finance.          | Reduced income.                                       | Support to maintain   |
| 1                 | Additional costs.                                     | employment.   |
|                   | Debt or money worries.                                | <ul> <li>Access to benefits such as<br/>Carers' Allowance.</li> </ul>   |
|                   |   | <ul> <li>Help with heating / travel costs.</li> </ul>                   |
| Life Balance.     | Reduced ability to                                    | Respite / short break.  |
|                   | socialise.  | Additional services for the   |
|                   | <ul> <li>Feeling too tired /<br/>stressed.</li> </ul> | cared for person.   |
| Future            | Careers advice.                                       | Support groups and activities   |
| Planning.         | <ul> <li>Training opportunities.</li> </ul>           | for carers.   |
|                   | Socialisation.  | Information and advice.   |
| <b>Employment</b> | Unable to work.                                       | <ul> <li>Additional help with care.</li> </ul>                          |
| and Training.     | Reduced hours.  | Support from employers:   |
|                   | Restricted opportunity.                               | flexibility and understanding.  |
| Living            | Adaptions.  | <ul> <li>Information and advice.</li> </ul>                             |
| Environment.      | Location.   | <ul> <li>Link to relevant services to support.</li> </ul>               |
| Education.        | Access to education.                                  | Information on opportunities  |
|                   | Restrictions on positive                              | available.  |
|                   | destinations.   | <ul> <li>Young carers supported in<br/>schools, colleges and</li> </ul> |
|                   | <ul> <li>Ability to engage with education.</li> </ul> | universities.   |
|                   | oddodion.   | Additional help with care to  |
|                   |   | enable participation in education.                                      |

## **Background**

On 1 April 2018 the Carers (Scotland) Act 2016 came into effect. The Act aims to give adult and young carers new rights, whilst bringing together all the rights carers currently have, under one piece of legislation. The Act places a duty on local authorities and health boards to prepare a local Carers' Strategy. Orkney's strategy encompasses all ages and relates equally to young carers as it does to adult carers. The strategy sets out how Orkney Health and Care (OHAC) intends to deliver the requirements of the Act, particularly in relation to:

Identifying both adult and young carers.

- Understanding the care that they provide and their support needs.
- Providing comprehensive and easily accessible information on the type of support available as well as how and where to get it.

Importantly, the Act brings changes to how carers can access support through 'Adult Carer Support Plans' and 'Young Carers Statements'. Under previous legislation, a carer had to provide 'regular and substantial' care in order to access a support plan. This has been removed and all carers are now entitled to a support plan if they want one.

Additionally, the new Act requires a focus on assessing the needs of the carer separately from the needs of the cared-for individual.

The Act also brings a range of new duties and powers:

| Adult Carer Support Plans and Young Carers Statements. | Adult Carer Support Plans will replace carers assessments and consider a range of areas that impact on a carer. Young Carer statements must also be produced.      |
|--|--|
| Eligibility Criteria.                                  | Eligibility Criteria for access to social care services for carers must be published. However, not all support offered to carers will be subject to the criteria.  |
| Carer Involvement.                                     | Carers must be involved in both the development of carers services and in the hospital discharge processes for the people that they care for.                      |
| Local Carers Strategy.                                 | Local Carers strategies, such as this one, must be produced and reviewed within a set period.  |
| Information and Advice.                                | An information and advice service must be provided for relevant carers, with information and advice about rights, advocacy, health and wellbeing (amongst others). |
| Short Break Statements.                                | To prepare and publish a statement on short breaks available in Scotland for carer' and cared for persons.   |
| Charging.  | Services provided for carers cannot be charged for. However, if the care is for the services users then normal charging policy will apply.                         |

#### Governance

Orkney Health and Care is committed to delivering on the nine National Health and Wellbeing Outcomes. Outcome six is: "People who provide unpaid care are supported to reduce the potential impact of their caring role on their own health and wellbeing."

Orkney Health and Care's commitment is that the significant role of unpaid carers will be recognised, that their views will be included, that their health and wellbeing will be nurtured and the impact of their caring role on their everyday lives reduced.

Furthermore, Orkney Health and Care will ensure that young carers are seen as children and young people first and foremost, and that any caring responsibilities that they undertake are appropriate and have regard to their age and maturity.

## **Development and Delivery**

The development of this strategy was coordinated by a Steering Group with representatives from Orkney Islands Council, NHS Orkney and the third sector, through the establishment of a Carers Strategy Group. It will be further developed, through input from carers themselves, following the consultation process.

The Strategy will be published within the Scottish Government timescales and will be reviewed and refreshed within 3 years of publication. It will be published on the Orkney Islands Council and NHS Orkney websites.

Finally, to ensure that delivery of the plan remains on track, the Steering Group will develop an action plan, ensuring that The Act and Guidance is adhered to.

## Vision, Principles and Values

We recognise that our services across health, social care, education and third sectors need to better support children, young people and adults in a caring role including, in some areas, improving practices and culture. Without carers vital contribution the health and social care 'system' could not survive.

The focus of Orkney Health and Care is on support in the community, rather than institutional care; increased personalisation of services and choices; and working to improve the outcomes for carers, whether adult or young carers. In addition, the partnership is seeking to tackle health inequality and developing a stronger preventative emphasis to its activities and interventions.

#### Vision

Our vision is that organisations communities and citizens work together to ensure that carers in Orkney are fully valued, respected and supported and that their vital contribution is recognised.

## **Principles**

Equal Partners in Care (EPiC) is a joint project between NHS Education Scotland (NES) and the Scottish Social Services Council (SSSC) aimed at achieving better outcomes for all involved in the caring relationship. The project has a set of core principles which were developed in consultation with a wide range of stakeholders and are based on key outcomes. These are very relevant to this strategy and as such we have adopted these as the best practice we will work to.

The 'Equal Partners in Care' (EPIC) Principles are:

1. Carers are identified.

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

#### **Values**

Values are a set of accepted standards. Our values for this strategy are noted below. These underpin everything we do from communicating with carers, to designing services, to planning for and providing support.

| Values.   | Equality of access.   |
|-----------|---|
|           | High Quality.   |
|           | Collaboration.  |
|           | Integration.  |
|           | Localisation.   |
| Strategy. | <ul> <li>Identify all those with a caring role in Orkney (even those who<br/>may not see themselves as carers). (EPiC Principles 1 and 6).</li> </ul> |
|           | <ul> <li>Meaningfully engage on an ongoing basis with carers. (EPiC<br/>Principle 2).</li> </ul>  |
|           | <ul> <li>Support carers to maintain their health and wellbeing. (EPiC<br/>Principles 3 and 5).</li> </ul>   |
|           | <ul> <li>Increase the profile of carers and the recognition of their unique<br/>contribution. (EPiC Principles 4 and 6).</li> </ul>                   |
|           | Further develop our staff to increase carer support. (EPiC Principle 2).  |

## **Equality, Diversity and Human Rights**

The principles of equality, diversity and human rights are the basic rights for all carers. Carers reflect the diversity of Scotland's population. We will work to ensure that carers are aware of their rights under the legislation and that no carer is disadvantaged owing to age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity, race; religion or belief; or sex or sexual orientation, in line with the Equality Act 2010.

All children and young people have an established set of rights and principles based on the United Nations Convention on the Rights of the Child. These say that nobody should treat a child or young person unfairly and that when adults make a decision about a child or young person it is what's best for the child or young person that should be the most important thing to consider. The child or young person must have their say too.

Awareness of their rights, and those of the person that they care for, can help adult or young carers get fair access to things that most people take for granted.

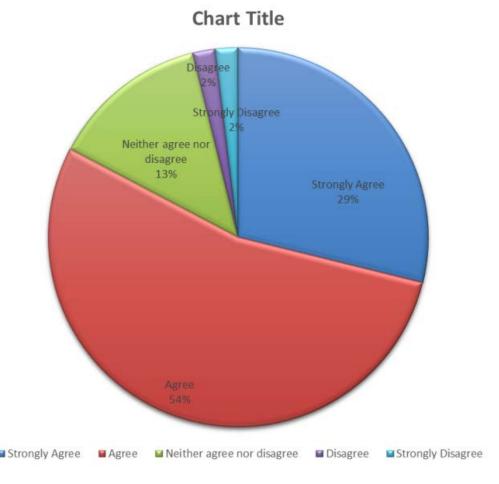
## **Consultation and Engagement**

The views of all stakeholders were sought to inform and validate the draft Carers' Strategy. This included:

- Unpaid Carers.
- Social Workers.
- Home Care Workers.
- Community Occupational Therapists.
- Third sector support agencies.
- Orkney Opinions Group.
- Primary Care Workers (via the Primary Care Newsletter).

The consultation took the form of a survey, with responses sought in writing, by email, via the Smart Survey online platform, or from the Orkney Opinions group.

Respondents were invited to say whether they believed that the four statements (referred to above) focussed upon the right issues, with 83% either agreeing or strongly agreeing.



The consultation also asked if anything was missing from the strategy, along with suggestions as to how the draft strategy could be improved.

A small number of respondents felt that the statement failed to address the right issues; however, those respondents also commented that they were not currently recognised as unpaid carers, nor did they receive the support that they felt they need. This strategy attempts to address this issue by saying how we will raise awareness of unpaid carers in the community, as well as make carers aware of how they can access the support that they need.

The following table shows a summary of the comments received, along with our response:

| Comment.   | Response.  |
|--|--|
| I am an unpaid carer and receive no support, whatsoever.   | The strategy addresses how OHAC and their partners will raise awareness of unpaid carers, as well as make them aware of how and where they can seek the support that they need.  |
| How do unpaid carers find out about the support available to them?   | Please see the response, above.  |
| Siblings of supported children are negatively affected by the circumstances in the home – should they be acknowledged as young carers, even if they are not delivering the care? | We recognise that this is a significant issue and seek to identify such children and address their support needs through the relevant Children in Need legislation.  |
| The strategy mentions adult carer support from Crossroads; is this not also available to young carers?   | Crossroads do, indeed, provide carer support services for young people. This has been clarified in the strategy.   |
| Vicarious trauma associated with caring for loved ones should be acknowledged and support provided.  | The Carers Act makes explicit provision of support to meet the carer's needs. This strategy will ensure that health and social care professionals are increasingly aware of the needs of carers, both during and after their time as a carer, so that they receive the health and social care services that they need. |
| Will increasing health and social care integration lead to a more formal role of carer assessment amongst health staff?  | All health and social care professionals can make a carer referral. OHAC will continue to raise awareness of unpaid carers, amongst health staff, as well as their role of identifying the support needs of carers and making appropriate referrals.   |
| The provision of respite care should be seen as a service for the carer, as a health preventative measure, rather than the cared-for person and, as such,                        | The Integration Joint Board (IJB) is funded by Orkney Islands Council (OIC) and NHS Orkney, with the IJB using the funding to commission services from both the NHS and OIC.   |

| should be funded by health as well as social care services.  |   |
|--|---|
| The strategy needs to say more about how young carers will be supported in the transition to adulthood, especially if they are seeking further education or employment opportunities outwith the county. | If existing adult or young unpaid carers are unable to continue the care support that they currently deliver, an appropriate package of care provision will be discussed and agreed with the cared-for person.  |
| The strategy looks good on paper but may not work well, in practice.   | The Carers' Strategy is our commitment to provide the care and support services that our carers need. The strategy will be constantly reviewed to ensure that the services delivered are consistent with the commitments made in the strategy. Furthermore, the strategy will be fully refreshed and published every three years. |

## **Carers in Orkney**

#### **Definition**

The Carers' (Scotland) Act 2016 defines a carer as:

"an individual who provides or intends to provide care for another individual (the "cared-for person")"

A "Young Carer" is someone who is under the age of 18, or over 18 but still at school.

An "Adult Carer" is someone who is 18 years old or over and not a Young Carer.

#### Who are carers?

A carer can come from all walks of life; be any age, including young children, employed, in education or neither, and have other family responsibilities. The lives of children and young people within a family environment, who are not the direct caregiver can, nonetheless, be significantly affected by the caring situation.

A carer can provide care for a few hours a week or 24/7. The care they provide can be light touch or intensive. Some carers have to care for more than one person, which presents unique challenges. They may have had a caring role their whole life or it may be for only a short time.

The "cared-for person" can often be a family member, friend or neighbour. They can also be young or old and have a range of care needs from support within the home, to help with getting out-and-about, to end of life care. Some cared-for people may have multiple care needs.

Many people providing care do not see themselves as a 'carer'. They are, first-and-foremost, a husband, wife, son, daughter, or friend, who is undertaking acts of kindness, perhaps sometimes seen as duty, for their loved one.

There are, however, some communities of carers we know very little about, most notably: refugees, asylum seekers, the travelling community, and carers who themselves have disabilities, including learning disabilities.

For the purposes of the legislation and this strategy though, all these people are defined as "carers". The term carer, used throughout this strategy, refers to those in an unpaid caring role.

As the types of carer are varied, the approaches we take to support them must also be diverse and nuanced. A one size fits all is not going to work.

#### The number of carers in Orkney

It's difficult to estimate the numbers of adult carers for a number of reasons, including:

Caring activities can often be seen as just a part of the relationship and the term 'carer' can seem alien to people.

Caring often starts at a low intensity so can go unnoticed.

Accepting the identity of carer means acknowledging the other person needs care, which can be difficult.

There may be a general lack of awareness of the role of a carer

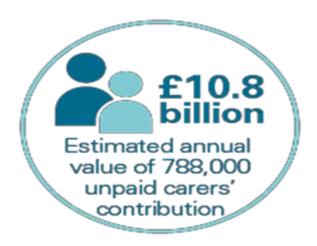
Accurately identifying the number of young carers is even more challenging. Many young people will not identify themselves as a young carer for a number of reasons:

- They do not realise that they are a carer or that their life is different to their peers.
- They don't want to be any different from their peers.
- They believe that the school will show no interest in their family circumstances.
- They want to keep their identity at school separate from their caring role.
- It's not the sort of thing they feel can be discussed with friends.
- There has been no opportunity to share their story.
- They are worried about bullying.
- They worry that the family will be split-up and taken into care.
- They want to keep it a secret and/or are embarrassed.
- They see no reason or positive outcome as a result of telling their story.

It is our responsibility to educate not only professionals to assist in the identification of adult and young carers, but also to inform them and, in terms of young carers, the people who support them, of their right to identify themselves as a carer if they so wish, and what this would mean for them.

The Scottish Health Survey (SHeS) estimates that there are 759,000 adult carers and 29,000 young carers (under the age of 16) in Scotland.

These individuals are critical to health and social care in Scotland, as the estimated value of the care provided is huge and nearly the equivalent of the entire NHS Scotland budget: <a href="http://www.audit-scotland.gov.uk/reports/e-hubs/transforming-health-and-social-care-in-scotland">http://www.audit-scotland.gov.uk/reports/e-hubs/transforming-health-and-social-care-in-scotland</a>.



Furthermore, according to the report Scotland's Carers (2015) (Scotland's Carers (2015) Report <a href="http://www.gov.scot/Resource/0047/00473691.pdf">http://www.gov.scot/Resource/0047/00473691.pdf</a>), the Scotland Census 2011 (Scotland Census Results and Data <a href="http://www.scotlandscensus.gov.uk/census-results">http://www.scotlandscensus.gov.uk/census-results</a>) may be a poor reflection of the number of carers in Scotland.

Whilst the census identified that 10% of Scotland's population are carers, the Scotlish Health Survey (SHeS) estimates this figure at 17% of the adult population.

The main difference between the two surveys appears to be those carers who only care a few hours a week. Generally, the SHeS is thought to provide the best estimate.

This means we could have up to **3,684** carers in Orkney.

There is a significant gap between the maximum number of carers we know about in Orkney (1,978) and the maximum potential number of carers (3,684). We have a huge challenge on our hands to close that gap. We will attempt to do this by:

- Raising awareness generally about the caring role.
- Training staff to recognise carers.
- Improving our communication to consider how this reaches carers.
- Implementing the "Think Young Carer" approach.
- Investigate the creation of a Carers Database.
- Maximise the opportunity for identification of and engagement with carers at any and all events the partnership and its partners hold.
- Promote the role of the Integration Joint Board carer representative and explore ways to improve carer access to them.

## Support currently available for carers

This section of the strategy details what support is currently available for carers in Orkney:

- Within Orkney Health and Care there is provision within the National Eligibility Criteria for a consideration of the risks and priorities relating to carers. As with the criteria for any social care service, risks must be substantial or critical to be eligible for support. Eligibility Criteria for carers was developed specifically in line with the requirement of the Carer (Scotland) Act 2016. The Carers Assessment has been reviewed in consultation with carer representatives and is made available to support the development of Adult Carer Support Plans.
- Orkney Health and Care commissions a third sector provider, Crossroads Orkney, to provide a Carers Support Service for adult carers over 18.
- There are many more other informal supports for carers available. These range from third party partners who, although not directly commissioned to deliver carer support will do this at the same time as they are delivering services to the cared-for person. The support carers need can often come in the form of existing services such as the Citizen's Advice Bureau, Housing, Energy, Benefits or Financial Advice teams, Mental and Physical Health Services etc. Friends, family, neighbours and existing social and faith groups can also be a source of valuable support for carers. In many cases the support required for the carer is to put them in touch with these groups, help them make the connection and encourage them to make full use of what is available
- If existing adult or young unpaid carers are unable to continue the care support that they currently deliver, an appropriate package of care provision will be discussed and agreed with the cared-for person.

## Our strategic intentions in relation to carers

We have a profile of the carers in Orkney and a sense of the scale of the number of carers we are yet to identify. We also have an understanding of the impact that the caring role can have, and we know the support that is currently available to carers. This information has led us to develop a number of strategic intentions in relation to carers which will enable more carers to identify as such; to enhance and improve the support available to carers; to reduce the impact of the caring role, and to involve carers more in the design and delivery of services both for carers and for the people they care for. In Orkney, we want to ensure that we get it right for all adult and young carers.

The following paragraphs provide a high-level overview of our strategic intentions, grouped under each of the statements of achievement. The Action Plan, (attached at Annex 1) contains more detail on how and when we will deliver. Successful delivery of the Action Plan will be driven and managed by the Carers' Strategy Group. consisting of senior officers of Orkney Health and Care, as well as third sector partners and the Integration Joint Board carers representative.

The financial challenges we face are acknowledged and whilst funding is limited we will aim to target what funding we have to those carers and services that need it most. We will maximise opportunities for access to existing support and services

available within the partnership, the Council, partner organisations and in the carer's family network and the wider community.

# Statement 1: I am supported to identify as a carer and am able to access the information I need

Orkney Health and Care Assessment teams provide advice and information about carer rights and offer Carer Assessments and Care Plans. NHS Orkney staff deliver advice and information, liaise with carers and refer carers to the appropriate agencies for carer assessments, whilst Crossroads Orkney will continue to support carers and ensure that they are aware of the services available to them.

Recognising that carers come from all areas of our population, we will seek to engage with them in a variety of ways that is appropriate to their needs, but also familiar to them. For example, we will utilise social media such as Facebook and Twitter. All communication and engagement will take account of any particular needs of carers in relation to the nine protected characteristics as described by the Equality Act 2010.

We will work to develop and manage the information available to all carers, ensuring that it is continuously updated and improved. The type of information made available to carers will be:

- Information on their rights, including those set out in the Carers' Charter.
- Income maximisation.
- Education and training.
- Information on the role of the Named Person in supporting young carers under the age of 18.
- Advocacy/Brokerage.
- Health and wellbeing.
- Bereavement support.
- Emergency care planning.
- Future care planning.

It is clear that we need to increase the identification of young carers in Orkney. It is our responsibility to educate not only professionals to assist in this, but also to inform young carers and people who support them of their right to identify themselves, if they so wish, and what this would mean for them. We will ensure that we sensitively identify young carers within schools via awareness raising, training and continuous professional development, building on the principles of GIRFEC.

A series of awareness raising events will be run to help people understand the role of adult and young carers and the challenges that they face and we will maximise every opportunity at other events and in other strategies, policies and guidance to raise the profile of carers and enable people throughout Orkney to identify as a carer, if that is what they wish to do. This will include supporting people to end their caring role if that is what they wish to do.

# Statement 2: I am supported as a carer to manage my caring role

Eligibility criteria make it clear what support and advice is available for anyone who does not meet the criteria for formal, funded support. In preparing the eligibility criteria our partners at Crossroads Orkney involved and consulted with carers. The criteria will be reviewed every three years in line with the Carers' Strategy.

Orkney Health and Care already has an assessment process which identifies outcomes and needs for social care services and also what support is provided to meet those needs.

Orkney Health and Care will review the template and the processes used for these assessments in order that they meet the needs of adult carers under the new legislation and are able to inform the support plans. In particular, we will ensure that emergency arrangements and future planning are areas that are covered in these plans in order that carers can successfully plan for periods of transition or crisis. We will give consideration to those caring for the terminally ill, ensuring that they plan for their life after caring, including young carers who may be left without a parent or other significant adult in their lives.

We will develop Young Carers Statements (YCS) to provide a framework for the identification of individual needs and personal outcomes, based on the SHANARRI indicators, for supporting young carers who have been identified either by a professional or by themselves. A YCS is separate from other forms of assessment that a young person may be entitled to, such as a Child's Plan or Co-ordinated Support Plan (CSP). This is to address some of the barriers that prevent young carers being identified.

A YCS will include the nature and extent of care provided, or to be provided, as well as the impact of caring upon the young carer's wellbeing and day-to-day life. It will also include information about whether a young carer has in place arrangements for emergency care planning (sometimes referred to as contingency planning), future care planning, anticipatory care planning and advanced care planning (for when the cared-for person is receiving end of life care). A YCS will also show if support should be provided in the form of a break from caring.

We will ensure that we have clear procedures about who will complete a YCS, how it will be completed and by when. We will look at the role of the Named Person, school nurses and any commissioned services to ensure that the most appropriate person undertakes the assessment.

Young carers will be provided with information about what to expect when they request or accept the offer of a YCS. All Statements will be reviewed within a given time frame, particularly if the health of the young carer or the cared-for person deteriorates, or if the cared-for person is being discharged from hospital.

A key stage for young carers is the point at which they transition from being a young carer to an adult carer. This age group is often characterised by life transitions such as the transition to college, university and work; living away from home; wanting to reduce the caring role; or not wanting to be a carer at all. These

may impact upon and change the caring role and/or the need for support. This should be reflected in the YCS.

When a young carer transitions to being an adult carer, the YCS will still be considered relevant until an Adult Carer Support Plan has been provided. We will not wait until the young carer reaches 18 to start this process.

We will also seek to maximise the opportunities for carers to access support groups and activities. As required by the legislation, we will prepare and publish a 'Short Breaks Services Statement' by 31 December 2018. The statement will cover both traditional and bespoke commissioned respite services and endeavour to provide more innovative and flexible arrangements.

A 'Short Break' will be further defined as a short break away from the caring role. Short Breaks will be based on assessed needs and will be outcome focused. Our aim is that Short Breaks will be planned, reliable, and positively anticipated by carers and the cared-for person. We also recognise that young carers may need to combine their caring role with other family activities, responsibilities, education and employment.

Recognising the Social Care (Self-directed Support) (Scotland) Act 2013 and the fact that carers are entitled to have choice and control over how their support is delivered, we will ensure that, as part of the process to prepare the Adult Carer Support Plans and Young Carer Statements, that the four options are explained and offered to all carers who are eligible.

# Statement 3: I am respected, listened to and involved in planning the services and support which both I and the person I care for receive

Engaging with service users and carers is vital in ensuring that services and support which are delivered are high quality and appropriate. We will ensure continuous dialogue with service users and carers that will ensure they are involved in planning services and support for both carers and cared-for people. This will include hospital discharge and commissioned services.

In terms of hospital discharge we will review patient admission documentation to ensure that it prompts consideration of and engagement with carers at an early stage, building on our person-centred approach.

The Carers (Scotland) Act 2016 brings a number of new and different obligations for staff and we will ensure that they are trained appropriately to understand these responsibilities and also in the use of the Service User and Carer Engagement protocol.

It is essential that we know who our carers are in Orkney. We will work with colleagues at Crossroads Orkney to develop and maintain the database of all known carers, which will be used for communicating and engaging with them. The database will be developed and maintained in full alignment with relevant Data Protection legislation, based entirely on an informed and explicit willingness of carers to be included in this.

There is one carer representative on the Integration Joint Board and we commit to provide ongoing support to them to ensure that their voice is heard appropriately.

We aim to involve young carers in every step of the implementation of the new strategy from the development of the YCS to what is needed from a young carers service. We need to take into consideration young carers willingness to take part and ensure that any involvement meets their needs as well as ours.

# Statement 4: I am supported to have a life alongside caring, if I choose to do so

All of our strategic intentions are about ensuring that carers are supported to have a life alongside caring if they choose to do so. We will monitor the implementation of the strategy and report on this regularly and appropriately to ensure that it is having the desired effect on reducing the impact of caring upon the health and wellbeing of carers.

In addition, we will review the strategy after 3 years.

## **Carers' Strategy Survey**

## **Full Responses**

#### Q1. The Strategy makes 4 key statements:

Statement 1: I am supported to identify as a carer and am able to access the information I need.

Statement 2: I am supported as a carer to manage my caring role.

Statement 3: I am respected, listened to and involved in planning the services and support which both I and the person I care for receive.

Statement 4: I am supported to have a life alongside caring, if I choose to do so.

Please tell us if you think that the Statements are focusing on the right things:

| Strongly Agree             | 15 |
|----------------------------|----|
| Agree                      | 28 |
| Neither agree nor disagree | 7  |
| Disagree                   | 1  |
| Strongly Disagree          | 1  |

#### Q2. Please tell us if the Statements have missed anything.

- 1 When caring 24/7 for my mother of 90+ I woul have been grateful for an NHS key worker. As the situation deteriorated, and I could no longer take mum to the GP surgery, we were left dealing with which ever GP or nurse was on duty, all continuity of care and relationships were lost.
- 2 -.
- 3 -.
- 4 -.
- What about the ongoing trauma experienced by carers in the aftermath of care, when the person they have been ,caring for is now in hospital , in another form of care or has died or recovered. What about acknowledging that carers benefit from trauma informed support through transitions and after their role as career has stopped.
- What about the ongoing trauma experienced by carers in the aftermath of care, when the person they have been ,caring for is now in hospital , in another form of care or has died or recovered. What about acknowledging that carers benefit from trauma informed support through transitions and after their role as career has stopped.
- 7 Yes.
- 8 -.

- I hate being an unpaid carer on top of my full-time job and having to plan everything in the house from meds to food to finances. Many times I am at the end of my tether and there is no support for me, no help for me, no respite for me on top of my job I do at least 20 30 hours a week on household things that should be shared by a spouse but aren't because the spouse is unable to manager but doesn't feel we need assistance in the home.
- 10 -.
- 11 -.
- 12 I often see siblings who are affected by the parents providing a caring role to their brother or sister. Parents are often very clear they do not want the siblings of the child with additional needs to be providing direct care, even if the sibling themselves may want to help in some way. Parents sometimes aren't available to help with sibling's homework, taking them to / from activities or siblings may not be able to have their friends over as this may be difficult for the cared for child to cope with or just too much for exhausted parents to manage alongside their caring role. In terms of a young person identifying as a young carer, because they are not directly involved in the provision of care, young carer may not be what they or their parents identify with, yet their day to day lives are very much affected by their parent's absence as they provide care for the child with additional needs.
- 13 Statement 4 does not explain how a person who is a 24/7 carer can possibly have normality; they need more help.
- 14 It is not very expansive on te transition from Young Carer to Adult carer. I worry that young carers find their life opportunities severely limited by their carer role, especially at ts very important transition point. I wold like to see more about what will be done if a young carer needs or wishes to leave the county to further teir education or to take up employment opportunities.
- 15 I think they cover well but there can be various situations not easy to cover.
- 16 Financial support.
- 17 The strategy looks good on paper but having been a carer it does not work so well in practice. ore sympathetic communication with carers is required. Listening to what they need and want would help as well. I realise there are funding problems, but walking over requests for help does not put the service in a good position.
- 18 1. Is bland.
  - 2. Manage in terms of this role is a misnomer.
  - 3, This is fine.
  - 4. Excellent statement.
- 19 -.

#### Q3. Do you have any further comments or suggestions regarding the Draft Carers' Strategy?

- 1 I believe there should be a right to a key health and a social care person who are obliged to make regular contact at increasing frequency as the caring role increases. The minimum frequency levels require to be prescribed.
- 2 -.
- 3 -.
- 4 The emphasis on Young Carers is very welcome. The strategy refers to Crossroads currently providing support to Adult carers over 18. I believed there was also support to young carers locally??

- 5 The strategy as a whole addresses many issues and identifies the impact on young carers, which is very positive.
  - I believe that the strategy as a whole doesn't acknowledge how traumatic events experienced as carers at any time in life can impact on well being.
  - It's also important to acknowledge that vicarious trauma can impact the carer through the nature of intermittent/emergency responses and ongoing caring responsibilities. We also need to acknowledge transitions in care and ongoing support after a carer ceases to be a carer while still experiencing ongoing distress, loss and trauma.
  - My experience as a bereavement counsellor and abuse survivor support worker and the feedback I receive from carers and survivors of abuse leads me to believe that many carers experience direct trauma and vicarious trauma as a result of their proximity to a loved ones suffering & traumatic experiences, medical interventions, pain management, inconsistent support and end of life protocols. Some professionals are working with trauma informed practices but many are not, and this can lead to more complex issues and impact on the carers ability to care and to recover from being a carer when that role is no longer required.
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- 7 -.
- 8 -.
- 9 Statement 4 is terrible: People want to have a life outside the insular, isolated world of caring. However, it is difficult to manage beyond just making a living to survive. I would love to have a better paying job but it is very difficult to move up the career ladder when one is stuck being a carer. Where are the employment professionals who can help us find self worth and help us update our CVs? As a carer I feel very discriminated against for job prospects.
- 10 How do carers know what information is available for them, and how do they access this information?

How do carers know what support us available to them? Without knowing this, how can they identify it they are fully supported?

What is being done to ensure that carers are involved in policy-making and to be informed of what opportunities are available for them to influence policy?

- 11 There was a role and expectation with the original carers assessments which came along with the Community Care Act for NHS staff to complete carers assessments not just social workers. Care managers included AHP staff, community nurses etc. We seem to have moved away from this joint working. Will there be a more formal role for NHS staff to be more involved now again with carers within the integration framework?
- 12 I have a question which reflects on my experience of working with people with significant health and care needs. I often see the impact to carers in terms of their own emotional health and physical health. The more intense the caring role and the longer this role lasts, which in our client group can be the lifetime of the client, the more significant the impact. It seems this strategy is aiming to recognise this impact on the carer and traditionally respite provision for the cared for person supported and sustained this caring and cared for relationship. This responsibility in terms of provision of respite sits as a social care provision. I am curious as to why provision of respite is seen as a service for the cared for person and isn't seen as a positive preventative strategy to maintain the carers health. If it was viewed this way then should this not be a shared responsibility financially between health and social care? One example of my work experience has been, carers continuing to carry on with their caring responsibilities and their own mental health deteriorating. The carers attend the GP and are prescribed anti-depressants. Or due to frequent manual handling for the cared for person the carers develop physical health problems themselves whereas regular carer breaks may support better physical and mental health for the carer which is a responsibility for health. In terms of statement 4: if the carer chooses to work and the child needs care after school. Most families have a family member or a childminder to provide that care but if the child has very complex needs then this is likely to be beyond the childminders experience. Respite can then be
- 13 There is no such word as adaption should be adaptation. The word carers should only be followed by an apostrophe when it indicates that what follows relates to those carers. There are numerous apostrophes in this document which should not be there.
- 14 It's just a little thing, but the plural of carer is carers. ie it does not have an apostrophe after the 's'. It's really irritating to see it written with an apostrophe almost everywhere in the document.
- As well as respite breaks. Daycare where the cared for person can get out (enable carer to attend work or education) and socialise, get exercise and stimulation 2 or 3 days a week.
- 16 I just hope it all comes to pass and help gets everywhere that is needed.
- 17 As a carer myself I don't think any of those things are happening at the present time.

difficult to secure if seen as a childminding service to enable the parent to work.

- 18 Don't think there is enough carers out there. Families often struggling to cope. Home carers need more pay. Old folks homes very expensive and not fair.
- 19 Consider supporting "young carers" during discussions in relation to statements 1-4 issues.

  "Support" should be an independent adult who has a sound knowledge of the case circumstances and is able to freely communicate with the young carer a bond of trust.
- 20 Financial support is top priority.
- 21 All carers regardless of age should get help and pay.
- 22 I do not have enough experience/knowledge to comment.
- 23 Practice what you preach. Communication between OHAC and NHS is not good. One hand does not know what the other is doing, experience has taught me that. People should not have to shout for what they need when they are at their most vulnerable. This must be even worse for young carers.
- 24 No. But who are carers 3rd last part.
  - "Reugees, asylum seekers & travelling community" Looks like this whole document is cut and paste as these are not applicable in a meaningful measure in Orkney.

| 25<br>26 | This is not relevant to my situation. I have no experience of being a carer or being cared for |
|----------|--|
|          |  |
|          |  |