



## Shetland Carer Information Strategy 2016 – 2020

**Date: 26<sup>th</sup> July 2016**

**Version: 6.1**

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**Review Date: July 2017**

### Document Control

<b>Title of Document</b>	Shetland Carer Information Strategy 2016 - 2020
<b>Committee Reference Number</b>	
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<b>Document Clearance</b>	<b>Date</b>
Adult Services Managers Meeting	18/5/16
Shetland Carers Strategy Group	26/4/16
Carers Forum	29/4/16
NHS EMT	11/8/16
Patient Focused Public Involvement Steering Group	29/8/16
Hospitality Management Team	25/8/16
Area Nursing & Midwifery Forum	9/8/16
Unst & Yell Carers Group	Sent out for comments Mar 16
Westside Carers Group	Sent out for comments Mar 16
Palliative Care	5/9/16
CSMT	1/9/16

<b>Date</b>	<b>Version</b>	<b>Group</b>	<b>Reason</b>	<b>Outcome</b>
January – May '16	V 1 - V 5	CIS Working Group	Amendments to text	V6
27 <sup>th</sup> July '16	V6	CIS Working Group 26 <sup>th</sup> July 2016	<ol style="list-style-type: none"> <li>1. Change of title to SCIS 2016 - 2020</li> <li>2. Update to Exec Manager Lead</li> <li>3. Changes from presenting at various meetings</li> </ol>	V6.1

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## 1 Introduction

Across Scotland today there are 759,000 unpaid carers, from the census in 2011, it has been identified there 2034 unpaid carers in Shetland. Shetland's first Carer Information Strategy was published in 2005 and since then the strategy has continued to be updated, most recently in January 2011.

The Health and Social Care Partnership in Shetland (Integration Joint Board (IJB)) is committed to six principles, which were developed by NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) which were commissioned by the Scottish Government to develop the Equal Partners in Care (EPiC) core principles for working with carers and young carers. The Core Principles are based on six outcomes for carers. These are:

- 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 free from disadvantage and discrimination related to their caring role
- carers are fully engaged in the planning and shaping of services
- carers are recognised and valued as equal partners in care.

This strategy outlines how Shetland will continue to support positive outcomes for carers using these outcomes.

### 1.1 Terminology

A range of terms is used to describe a person who cares for another including: 'unpaid carer,' 'carer,' 'family carer' and 'informal carer.' All partners involved in the development of this strategy prefer to use the term 'unpaid carer' or 'carer.' In this strategy we abbreviate 'unpaid carer' to 'carer,' as do many organisations and carers themselves. It is important that carers are not confused with paid workers, who are sometimes incorrectly called carers too: paid workers are support workers. Equally, carers are not volunteers. There may well be volunteers supporting the cared-for person and/or the carer, but they are not the carer.

## 2 Who Are Carers?

A carer is someone who provides unpaid care to a family member or friend. They may care for an older person, someone who is disabled, has a long-term illness, mental health problems or is affected by alcohol or drug misuse. They may be parents, spouses, grandparents, children, siblings, same sex partners, friends or neighbours. Carers can be any age, from children to older people, and from every community and culture.

Carers can be adults supporting adults; young carer caring for an adult or another young person; or can be a carer of a child with disability whether the carer is a parent or not. Some carers care intensively or are life-long carers. Others care for shorter periods. Some carers may be disabled or have care needs themselves. The carer does not need to be living with the cared-for person to be a carer.

Anybody can become a carer at any time, sometimes for more than one person.

### 2.1 Who are Young Carers?

Young carers are children and young people under the age of 18 years who in some way look after or support someone in their family who has an illness, a disability, or is affected by mental ill-health or substance misuse. Young carers often take on practical and/or emotional caring responsibilities that would normally be expected of an adult. The tasks and level of caring undertaken by young carers can vary according to the nature of the illness or disability, the level and frequency of need for care and the structure of the family as a whole. Sometimes young carers look after siblings, either because a parent is unable to due to their ill health or as respite for a parent who has a disabled child.

While we should not automatically assume that caring for others is a negative experience we must recognise that it can restrict young peoples' lives, and limit their experiences and opportunities as they grow up. Young carers are first and foremost young people and we should ensure that we have supports in place to enable them to enjoy as far as possible the same range of experiences as their peers, and to achieve their full potential in everything they do and aspire to.

### 2.2 Carers in Shetland

Procedures are in place to collect carers' contact details across the partnership. Carers are identified via a number of routes, the With You For You process for adults (Single Shared Assessment process) and GIRFEC for children. Information is shared on a case by case basis subject to the agreement of the client. GP surgeries have also been issued with a protocol for identifying carers. It is recognised that there is under-reporting of carers in Shetland, and work is currently underway to review the processes and identify unmet need.

### 3 Policy Context

A large amount of relevant legislation and policy documents shape services and support for carers. Below are some of key legislative and policy frameworks (this list is not exhaustive);

- Caring Together – The Carers Strategy for Scotland 2010-2015
- Getting it Right for Young Carers – The Young Carers Strategy for Scotland 2010-2015.
- The Care 21 Report – The Future of Unpaid Care in Scotland.
- UN Convention on the Rights of the Child
- Work and Families Act 2006
- Changing Lives: 21st Century Social Work Review (2006)
- Delivering for Health (2005)
- Community Care and Health (Scotland) Act 2002
- Carers (Recognition and Services) Act 1995
- Carers and Disabled Children Act 2000
- Children (Scotland) Act 1995
- Equality Act 2010
- Carers (Waiving of Charges for Support) (Scotland) Regulations 2014
- Getting it Right for Young Carer's, The Young Carer's Strategy for Scotland 2010-2015
- The Education (Additional Support for Learning) (Scotland) Act 2004, 2009
- The Children and Young People (Scotland) Act 2014
- GIRFEC - [http://www.shetland.gov.uk/children\\_and\\_families/GIRFEC.asp](http://www.shetland.gov.uk/children_and_families/GIRFEC.asp)
- WYFY documentation

Of particular note is the proposal from the Scottish Government to bring into law new legislation to further support carers in Scotland. This Bill was approved on 4/2/16 and the key elements within the legislation from April 2018 will be:

- To change the term Carer's Assessment. Many carers do not like the term, believing that it is judgmental and assesses their ability to provide care rather than considering what help they need to support their caring role. To address this issue and encourage carers to come forward, the Scottish Government have proposed a change of name to Adult Carer's Support Plan and Young Carer's Statement.
- To remove the "substantial and regular" test so that all carers will be eligible for a Carer's Support Plan. Under current legislation, local authorities only have to offer the assessment to carers who care on a regular and substantial basis. Currently there is no set definition for what is considered regular and substantial, and those carers providing low levels of support (no matter what the impact this has on them) are not eligible. This means that it can be more difficult to provide preventative support and carers may feel unable to access support until a crisis point is reached.
- To build in support for carers to ensure that there is a plan in place for emergencies.

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- These proposals are supported by national Carers organisations.

The key strategy document within Shetland is the previous Shetland's Carer Information Strategy and we have also used a number of local strategy documents to help with the strategy.

## 4 Drivers for Change

Local research shows that by 2020 we can expect to see a 3-fold increase in the number of people with disabilities who will need Community Health and Social Care services from the numbers in 2000. Population projections for the next 15 years predict an increase in the numbers of older people of approximately 40% and simultaneously a 15% decrease in the adult working population. Consequently the need for unpaid and family carers is going to grow for the foreseeable future. Carers are key partners in care provision alongside the statutory agencies and organisations in the voluntary and independent sector.

Providing carers with the right support helps to prevent them reaching crisis. To put it simply the cost of small and inexpensive interventions at the right time is far less costly than providing full time replacement care when a carer becomes ill or the caring relationship breaks down due to carer strain. A preventative agenda is the main focus for the future.

Integration of Health and Social Care is one of Scotland's major programmes of reform. At its heart, health and social care integration is about ensuring that those who use services get the right care and support appropriate to their needs, at any point in their care journey. Integration will ensure that health and social care provision across Scotland is joined-up and seamless, especially for people with long term conditions and disabilities, many of whom are older people. Further information on Integration can be found here;

[http://www.shetland.gov.uk/Health\\_Social\\_Care\\_Integration/default.asp](http://www.shetland.gov.uk/Health_Social_Care_Integration/default.asp)

The 9 National Health and Wellbeing Outcomes are high-level statements of what health and social care partners are attempting to achieve through integrated working and ultimately through the pursuit of quality improvement across health and social care.

Outcome 6 specifically refers to outcomes for carers 'People who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact of their caring role on their own health and wellbeing.'



## 5 Resources for Carers in Shetland

Some of the services provided for carers are listed below:

- A carers group is facilitated by staff at Annsbrae House to support carers of people with mental health problems.
- A group of carers of people on the autistic spectrum is facilitated by Community Care with support from the Bruce Family Centre, with a bookable 'crèche' (wide age range) to assist parents to attend.
- As well as running groups for people with Alzheimer's, Alzheimer Scotland also runs a sons and daughters group.
- Voluntary Action Shetland (VAS) has developed and facilitates the Shetland Carers Strategy Group (a multi agency group with carer representation who meet every six weeks at Market House), Lerwick.
- Central Carers Support Group meet monthly in the Market House carers centre Tues mornings 10.00 – 12.00
- VAS outreach support project is now working in the North Isles of Shetland.
- VAS Carers Newsletter is now compiled and sent out quarterly to any carers on the VAS or NHS Carer data base.
- VAS short breaks for carers is a partnership project with Shetland Care Attendant Scheme (SCAS) where a small budget allows carers to access care cover through SCAS providing a short amount of time of 'me time' for the carer to help reduce stress.
- VAS are members of the young carers action group and have started a new Lerwick young carers group and facebook page with promotional work starting in schools and youth groups.
- VAS hosts a local virtual carers website through <http://www.shetlandcarers.org/>
- Westside carers' support group in the West of Shetland.

A "Short break" (or respite care) is a break from normal routine designed to be of benefit to a carer of a person with a disability, long term illness or need. The Scottish Government has set national targets for increasing the amount of short breaks available. In Shetland the level of short breaks is high and increasing year on year. There are a range of short breaks available including:

- local authority provided residential short breaks for older people; older people with dementia; adults and children with learning disabilities and adults with mental health problems

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- local authority provided day services for older people; older people with dementia and children and adults with learning disabilities
- short breaks at home – Shetland Care Attendant Scheme
- short breaks in the community for children with disabilities provided by Shetland Islands Council.

Other services provided for vulnerable people in the community also help their carers by providing relief from caring tasks or by increasing the independence of the person for whom they provide care. These include:-

- care services delivered at home – such as personal care, community nursing, help with domestic tasks and meal preparation;
- occupational therapy;
- physiotherapy;
- speech and language therapy;
- psychological therapies;
- specialist equipment;
- adaptations to property;
- Community alarms & Telecare;
- Health Improvement – flu jabs and health and well being checks are offered

## **6 Governance**

The prime responsibility for provision of services to carers is held by the Single/ joint Accountable Officer in the Integrated Joint Board. Progress is monitored each quarter by the Directorate Management Team and Committee Members as part of the quarterly reviews. Any registered services used by the carers are regulated by the relevant bodies. The Shetland Carers Strategy Group is accountable for the action plan developed from this strategy.

### **6.1 Funding**

Many of the costs incurred by the statutory agencies in providing information, advice and support services for carers are included in generic service budgets.

## A Carer Speaks

“I have been a carer for nearly nine years now in which there have been massive changes in Shetland in social care, with a reduction in both staff and in services. On the positive side, the co-ordination and co-operation between services has improved, but the timescales in waiting for, for example, Occupational Therapy assessment, can be extremely frustrating.

Carers’ support services have improved a great deal over the period; we now have a Voluntary Action Shetland full-time carers’ support worker and the Virtual Carers Centre, as well as the CAB carers’ advice line and Advocacy Shetland provide advocacy services for carers; a counselling service is also available. Carers’ groups are now up and running in the North Isles, Westside and Lerwick.

On the whole the process of the Carer’s Assessment is increasingly understood both by those carrying it out and those they are supporting, but there is still a need for more training on the need for separate recording of the hopes and aspirations of the carer. Similarly there is a need for greater promotion of the advantages to the carer of an early support plan, enabling them to be signposted to advice and information so that the carer is well-prepared and informed once they have the need for more practical support; so much more effective than waiting until crisis point has been reached and the carer is no longer able to cope.

Identification of carers remains an issue, particularly in a culture such as ours where looking after your loved ones is just something that you do.

Finally back to peer’ support, which is great for carers. As well as the relief of having someone to talk to in a carers’ group who actually knows what you’re going through, there is the opportunity for some ‘me’ time without feeling guilty. Through my local carers’ group members have found out about practical things like C+ concession cards and free continence provision, saving them a lot of money. As the professionals gradually realise the economic value of carers, and the advantages of working in partnership with them, learning from each other will still be important.”

### **Adult Carer**

“Being a young carer is a challenge. It makes me feel different and alone. I didn't know I was a young carer until recently. Before that I just felt alone like no one understood how I felt. My mum has rapid cycling bipolar which means she experiences what we call highs and lows. My dad left us when I was six months old and he doesn't give us any support his family barely acknowledges my existence. I don't have any siblings living with me so I'm the only one who can really tell when she is going into an episode. Since I got young carer support my life has become a lot easier. I'm starting to do more independent things and I especially enjoy going on babble and sharing with people in the same situation. I no longer feel alone thanks to all the support.”

### **Young Carer**

## 7 National Perspective

*Research carried out by Carers UK estimates that around 1.25 million carers spend over 50 hours a week caring, and 45% have been caring for longer than five years.*

Source: Carers UK

The Scottish Government published the ***Caring Together: The Carers' Strategy for Scotland 2010 – 2015***, in July 2010. The key headline messages held within the strategy are the acknowledgment of the immense contribution that carers make to society and that without the valuable contribution of Scotland's carers, the health and social care system could not be sustained. It states that carers should be valued as equal partners in the planning and delivery of care and support. Activity should focus on identifying, assessing and supporting carers in a personalised and outcome-focused way and on a consistent and uniform basis.

Nationally there have been many developments at a strategic level, with the current Scottish Government making a commitment to introduce new legislation to support carers through the Carers Bill. The Carers Bill was introduced to the Scottish Parliament in March 2015 and the Act will come into force April 2018. This aims to provide a framework for recognising and supporting carers, however there are some areas where improvements could be made and a few areas where significant changes need to be made to ensure the Bill delivers real rights and real change for carers.

The Bill will:

- Improve identification of adult carers and young carers, and identify carers' needs for support more consistently by improving and renaming the carers' assessment process
- Place a duty on local authorities to support carers (subject to eligibility criteria) and to publish a statement on short breaks; there is also a power to support carers in preventative manner who do not meet eligibility criteria.
- Place a duty on local authorities to develop and publish local carers' strategies, and make provision for carer involvement in local services, local planning and in services provided to the cared for person
- Place a duty on local authorities to provide information and advice services to all carers.
- Place a duty on Local Authorities to ensure carers have an arrangements for emergencies

The 2001 Census asked a question about carers for the first time, giving us access to more accurate information about the numbers of carers across the UK.

## 8 NHS Shetland and Shetland Islands Council Overview

Shetland's first Carer Information Strategy was prepared jointly by NHS Shetland, Shetland Islands Council and the third sector as part of the implementation of the Joint Future Agenda locally. This was published in April 2005. Since then the Strategy has been updated, most recently in January 2011, and a new section summarising progress made on the implementation of the strategy has been added.

The Strategy helps statutory bodies to:

- Meet their statutory duty under the terms of the Community Care and Health (Scotland) Act 2002 to inform carers of their potential right to an assessment of need; and
- NHS Shetland to meet the requirement of the Patient Focus Public Involvement (PFPI) Initiative to have a strategy that meets the information needs of patients, relatives and carers.

Shetland's Community Health and Social Care Partnership (IJB) and Third Sector Organisations all recognise the valuable contribution carers, including young carers, make to the lives of the people they care for in Shetland. NHS and VAS have been awarded the Carer Positive award at the "engaged" level. This means they are engaged in providing a working environment where carers are valued and supported.

The Carer's Link Group is composed of representatives from these agencies and carers, NHS, SIC and third sector organisations, including VAS carers support service, local carers, Shetland Care Attendant Scheme, Shetland Befriending Service, Shetland Islands Citizens Advice Bureau, Alzheimer Scotland and Psychological services. Together they are working to try and find a shared vision for future service development. This is all being carried out through a partnership approach. This has paved the way for the development of a clear carers strategy action plan that will clearly show how carers will be supported in Shetland and enable them to continue with the valuable contribution that they make to the lives of those that they care for.

The last four years we have seen developments in the carer support offered by our third sector partner Voluntary Action Shetland carers support service who have one full time and one part time member of staff. They now offer carers assessments, 1-1 support, carer support groups, online support & information through the virtual carers centre [www.shetlandcarers.org](http://www.shetlandcarers.org) crafty carers group, young carers group, short break grants and carer training. Shetland Islands Citizens Advice Bureau and Advocacy Shetland offer carer support & advice and are independent from other carer services. Shetland also now hosts its own AlzheimerScotland Centre in Lerwick.

Following the lead from other local authorities, Shetland has used the EPiC principles throughout the strategy and all the actions within the plan link back to the EPiC principles. It is also very important that carers felt that they could contribute towards this strategy so they have been consulted so that the views contained reflect the opinions of Carers across Shetland. The Shetland Carers Strategy Group has reached the conclusion that *"We can't afford not to care for carers"*

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By 2018 the Shetland Carers Strategy Group would like to see the following for Carers in Shetland.

- Carers truly seen as equal partners
- Support plans put in place for all carers
- Quality implementation and review processes for carer support plans
- Measurable impacts on carer support plans
- Preventative investment in services for carers
- Help for carers when they need it
- Fast, responsive & flexible support
- The same support regardless of where you live

## 9 EPiC- Equal Partners in Care

The Shetland Carers Strategy Group adopted the EPIC model for our strategy. Equal Partners in Care (EPiC)<sup>1</sup> - NHS Education for Scotland & Scottish Social Services Council. Alongside each aim, are the key outcomes that carers and partners wish to achieve.

EPiC Aim for Carers	Key themes for carers and their partners in Shetland
To be identified	<ul style="list-style-type: none"> <li>▪ To be recognised as a carer</li> <li>▪ Assistance for carers to recognise themselves as carers</li> <li>▪ Assistance for parents of children with illness or disability to recognise themselves as carers</li> <li>▪ Assistance for young carers to be recognised as Carers.</li> <li>▪ To have information and support</li> <li>▪ Carer awareness training for health and social care professionals</li> <li>▪ Issues for disadvantaged and hard to reach carers with particular requirements</li> </ul>
To be supported and empowered to manage my caring role	<ul style="list-style-type: none"> <li>▪ To have appropriate, condition specific, training for carers</li> <li>▪ Easy access to meaningful Carer Support Plan / Assessment</li> <li>▪ Carer advocacy</li> <li>▪ Emergency planning</li> <li>▪ Supporting carers in their everyday lives (which could include working or school)</li> <li>▪ General Carer support, including psychological support</li> <li>▪ Condition specific information and support</li> <li>▪ Information on sources of support</li> <li>▪ Ensuring everyone aware of support resources for carers</li> </ul>
To be enabled to have a life outside caring	<ul style="list-style-type: none"> <li>▪ To have regular and appropriate respite using a Self Directed Support approach if appropriate</li> <li>▪ Benefits advice &amp; information</li> <li>▪ Work/Home Life Balance and for young carers to be supported to access education and play.</li> <li>▪ To be able to access social and community opportunities</li> <li>▪ Increasing job and volunteering opportunities for carers</li> <li>▪ Skilled, responsive and timely Care at Home service</li> <li>▪ Skilled in the use of technology</li> </ul>
To be fully engaged in the planning and shaping of services	<ul style="list-style-type: none"> <li>▪ Carers experiences - as carers - to be better understood</li> <li>▪ Involve carers in carer awareness training</li> <li>▪ Involve carers in research</li> <li>▪ Gather feedback from carers</li> <li>▪ Involvement in strategic planning and improvement groups</li> </ul>



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To be free from disadvantage or discrimination related to their caring role	<ul style="list-style-type: none"><li>▪ Recognition of carers as a diverse group</li><li>▪ Rurality issues that impact on caring</li><li>▪ End of caring / Bereavement support</li><li>▪ Carers Own Health</li><li>▪ Young Carers transition to Adult Services</li><li>▪ Training for employers / Employability</li><li>▪ Poverty</li></ul>
To be recognised and valued as equal partners in care	<ul style="list-style-type: none"><li>▪ Right to choose level of care to provide</li><li>▪ Partnership approach</li><li>▪ Involved in support plan of the cared-for person</li><li>▪ To be listened to</li></ul>

1 [www.knowledge.scot.nhs.uk/equalpartnersincare](http://www.knowledge.scot.nhs.uk/equalpartnersincare)

## 10 EPiC Aims for Carers in Shetland

### 10.1 Carers to be identified

Early identification can mean that carers receive support in order to enable them to continue caring for longer, with better outcomes for them and the person they care for. It is essential that a carer is identified and referred at the earliest opportunity after interacting with one of our services. There are three key areas for identification.

- To recognise yourself as a carer and be recognised as a carer
- For professionals to be carer aware
- To have information and support available for carers

**Current Position:** Shetland is currently in the position where they are starting to recognise more carers. A number of carer assessments have been made over the previous year from different areas. GP's are flagging some patients as carers and there is some information sharing between the different organisations. Two years ago the practice managers all attended a meeting regarding carer awareness. Young carers packs have been distributed to all schools.

There is a large difference between the identified carers on the shared database (190) and the numbers for the census information (2034). There are still problems with people actually identifying themselves as the carer and knowing the differences between paid and unpaid carers and people thinking that is what you do for your partner / mother. There are often issues with the cared for person not understanding how this is affecting the carer.

VAS provide carer support service that offers assessments, provides a regular Carers Newsletter, runs groups including Unst & Yell Carers Support Group, Crafty Carers, Young Carers Support Group, and a new Stepping Out Together initiative in Yell.

Alzheimer Scotland have a number of initiatives happening around Shetland including Memory Cafes, Sons and Daughter groups, Art sessions and singing sessions. These are mainly targeted at carers and cared for people with a diagnosis of Alzheimer's and dementia but they do accept other people in the group.

200 Carers' assessments have been carried out since 2010 with 59 being carried out in 2015. 190 carers are on the joint carers database.

For Young carers there are 5 supported by VAS and the SEEMIS system is showing 2. This is a low baseline and more work is required to check if this is a true picture.

**Issues to overcome:** The major issue that needs to be overcome is carers identifying themselves as carers, this is particularly a problem for young carers, who are even less likely to self identify. Sharing the information between the different organisations, over-reliance on leaflets not personal communication.. Young carers should be identified through GIRFEC processes which bring together children, young people and their families with those closely involved in providing support. Through GIRFEC processes well-being needs are identified and addressed. Children and young people should

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have their additional support needs, and this includes young carers recorded on the Schools database SEEMIS. all carers need to be encouraged to go on the shared database.

**Outcome to achieve** by 2020: To identify more carers at an earlier stage in their caring role, so that there is a truer picture of how many carers there are in Shetland. This will enable preventative strategies to be put in place to avoid carers reaching crisis point.

### Goals

- Continue awareness raising to ensure earlier identification of carers from 2016-2020
- Develop a shared database between organisations by the end of 2016
- Make the referral process and updating of information clear, ensure that this is not dependent on which organisation the referral has been made through, by the end of 2016
- Continue to promote young carers in schools pack
- Ensure all Young carers are flagged on the SEEMIS and the information is shared with VAS to develop and agree and implement a recording system for identifying numbers of young carers.

## 10.2 To be supported and empowered to manage my caring role

Carers have the right to request an assessment and local authorities have a duty to inform carers of this right. Services need to get better at finding ways of forming relationships and communicating with carers in order to give the carer the support they require to continue their caring role. There is also an obligation for the Local Authority to provide emergency planning support.

**Current position:** There are a number of carers groups in Shetland that support carers, these help to build up resilience and enable carers to support each other. Carers Support Plans are being carried out by a number of people and this will be updated alongside the guidance for the “With You For You” changes. Encouraging more people to take up the direct payments aspect of self directed support so that the support can both meet the needs of the cared for person and that of the carer, in 2016 there were approximately 40 people in Shetland using this form of support.

Carers who have been identified all say that the services and people they come into contact with are usually very supportive. Alzheimer Scotland have increased awareness of local support groups and have dementia resource guides. Shetland Care Attendant Scheme have a service level agreement with the council that provides approximately 400 hours of respite for carers per month. The virtual carers centre is now up and running and new ways are being looked at to support people in the use of ICT. There is also work being carried out with the Telecare Project manager to use some Assistive Technology that can take some of the responsibility from the carer and provide a back-up if anything happens when the carer is absent. Some carers have excellent coping mechanisms and good network support and the groups help to build up this resilience even more.

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The Young Carers identified by VAS are receiving 1:1 and peer support. It is increasingly important for them to receive appropriate information about the condition of the person.

Schools work to support children and young people with known or suspected caring roles by putting in place a range of strategies and interventions to support their access to education and learning. This includes support with homework, regular contact with key staff, increased communication between home and school and access to nurturing supports and activities where appropriate.

**Issues to overcome:** It is extremely important to ensure that all carers have access to carer support plan and emergency planning). This is included as part of the Carers Act and is essential for the peace of mind of the carer. Due to the lack of self identification, often the assessment and support is only offered once a carer is at breaking point. Carers are often not aware of the support planning process and there are some inconsistencies in how this is delivered, for example when are they offered and where they are signposted to, as sometimes professionals will focus on the cared for person rather than the needs of the carers. There needs to be a clear process for what happens to the Carer Support Plan or Assessment once it has been completed and it is essential that everyone in Shetland can access the same level of service. There are problems for carers accessing training support from SIC, NHS Shetland, e-learning access, independent providers. Some carers may not access support such as respite because of the cost, or a worry about the perceived or potential cost or due to a lack of transport or transport costs. Shetland has a number of challenges specifically with self directed support as there are no care agencies and employment is quite high; it can be particularly problematic in very rural areas.

**Outcome to achieve:** All identified carers to have been offered Carer Support Plan in place which covers support, training needs and emergency planning.

### Goals

- Promote the Carer Support Planning service throughout the SIC and with carers to ensure clear guidance is available to ensure consistency amongst carer support plans and young carer statements by end of 2016
- Build resilience in all communities throughout Shetland by introducing local support groups and use of the Virtual Care Centre, ongoing from 2015-2020
- Identify training needs of carers and implement a training programme for carers that begins to address these needs.
- Encourage carers to stay healthy by promoting well being checks for carers on-going throughout 2016
- Ensure carer support plans include an element of emergency planning so that there is an awareness of what would happen if the carer was not available.
- Continuing to raise awareness of the benefits of using self directed support for carers

### 10.3 To be able to have a life outside caring

Short breaks or respite care means a carer and the person they care for are supported so that the carer is able to have a break from their caring situation. This is an essential part of the support that families and carers need to continue caring. Short breaks should deliver positive outcomes for all involved in the caring relationship.

**Current position:** Some carers are being identified at an early stage which gives them access to the low level support they require and can help to ensure that they do not end up in crisis situation. Time away from caring can be the best stress relief and in Shetland there are some support services which are specifically being offered in order to give time out for carers from their caring situation. Shetland Care Attendant Scheme support gives carers a shortbreak, daycare is offered in the residential homes which again provides respite during the day. The GOLD Group is day care for older people with Learning Disability. All residential units have respite beds which are fully utilised, Newcraigielea is a local authority facility offering short break and respite to people with learning disability and autism. Also Laburnum offer short breaks for those with additional support needs. Money can often be a worry for carers in taking these short breaks but CAB provides a Carers advice line which can advise about the different benefits available and also in some cases self directed support is being offered which can help people to plan for their own personal circumstances. VAS applied for a “Time to Live” grant which can be used for carers caring for adults. In 2015 20 of these grants were given, with approximate value of £200 each. As part of the Young Carers group we have facilitated them receiving timeout from their caring role, this has either been through specific activities or reducing some of the barriers that they face, for example helping with transport.

**Issues to overcome:** Carers not planning respite and shortbreaks can lead to crisis situations for themselves which means services then have to respond to emergency unplanned situations which are a lot more difficult to manage. In Shetland, unlike the Scottish mainland there are a lack of Independent Community Care providers which can be a barrier to the uptake of direct payments from people who do not want the additional responsibilities of being an employer. It can initially make the role seem even more exhausting and complicated to take responsibility for everything. SCAS have some difficulties with recruitment of personal assistants which can sometimes mean there is less respite available through this organisation. Befriending uses volunteers and they also have experienced some recruitment problems. Finally for the carers there are problems when the cared-for person is not willing to attend respite.

**Outcome to achieve:** Enabling carers to be able to continue their caring role for longer with less use of emergency respite and more uptake of planned approaches.

**Goals:**

- Promote a range of social and networking opportunities to reduce carer isolation
- Ensure carers have appropriate respite breaks by promoting timeout activities for carers in conjunction with organising respite services for the cared for person.
- Promote self directed support and benefits advice through SIC and CAB, particularly working with CAB in their planned campaigns regarding maximizing incomes.

## 10.4 To be fully engaged in the planning and shaping of services

Engaging carers and the people they care for in planning and shaping services can result in better services and better outcomes for all involved.

**Current position:** Every carer should have the opportunity to input into WYFY process if the cared for person wishes this to happen. In Shetland there is an unpaid carer representative in the Scottish Carers Reference Group (and as a consequence the Carers Parliament), the Shetland Carers Strategy Group, Integrated Joint Board, IJB Strategic Planning Group, the Shetland Carers Strategy Group, and the Coalition of Carers in Scotland Rural group. A number of adult carers took part in the inspection into Older People Services in 2015. There is currently a Virtual Carers Centre set up and this website is being used to look at ways of offering distant support such as carers chat, already a Carers Rights question and answer session has been held. In Shetland we are working with the Mental Health Forum to follow the Triangle of Care: A Guide to Best Practice in Mental Health Care in Scotland, which is an alliance between service user, carer and staff member that promotes safety, supports recovery and sustains wellbeing. It assists staff to look at how they are identifying and supporting carers, and what needs to be done to improve and increase this. It provides frontline staff with the tools to better support carers as part of the care team and to work in partnership with organisations supporting carers

**Issues to overcome:** There are always difficulties for carers in leaving their role, so there needs to be other ways for carers to engage especially with geographical issues and dispersed communities. This can happen when the cared-for person dies, but also when they transition to permanent residential care. It is therefore important to engage and support carers in other ways apart from face to face. There are also some worries for young people engaging as they believe that speaking-up could be detrimental to the cared-for person. It is also important to be aware that many carers can feel guilty for asking for any help. and they may not understand that they have the choice to end their role as a carer.

**Outcome to achieve:** To ensure that carers are seen as an equal partner in the care delivered to the cared for person

### Goals

- Involve carers in carer awareness training that will be developed and delivered in 2017
- Ensure there are a different opportunities for carers to feedback, particularly using technology where possible by 2017.
- Continue to involve carers in the WYFY process that is taking place for the cared for person and consult them regarding the level of support they are able to provide - ongoing.
- To continue working with the mental health forum with their triangle of care model.
- Work with schools and other community groups to raise awareness of young carers and facilitate engagement and access.

Link Young Carers to other children services groups looking at wider participation and engagement of children's services and planning.

## 10.5 To be free from the disadvantage or discrimination related to my caring role

Carers must be free from disadvantage or discrimination related to their caring role as this can have an impact on their health, finances, work and education

**Current position:** This is being supported through GP's flagging carers on their system to inform them when there are flu clinics or health checks available, Alzheimer Scotland and VAS are both offering outreach support to help overcome geographical boundaries and transport is being provided to attend carer groups in outlying areas. VAS will support carers for up to two years when their caring role has ended. VAS and CLAN are able to access counseling through the Shetland Bereavement Support Service. The virtual carer centre is being used to engage with carers from rural areas, as well as providing support groups for these areas. Citizens Advice Bureau is offering outreach and home visits. Alzheimer Scotland promote dementia Friendly communities initiatives; raising awareness of dementia in the community, helping to reduce stigma and supporting e.g. shops, businesses, schools and generic groups to become more inclusive for people with dementia and carers. Shetland Islands Council has implemented not charging carers for support which they are eligible for, including replacement care in residential settings.

**Issues to overcome:** More research is required into finding out how many carers in Shetland come from minority groups including, ethnic communities, male carers, carers who are Lesbian Gay Bisexual and Transgender and the barriers they face. People living in rural areas can be discriminated against if they do not have transport or the money for it. Caring can have adverse effects on the carer's health; high blood pressure, back problems, exhaustion, depression. Caring can be stressful as carers are constantly worrying about the cared-for person, their financial situation; 'the lack of a life for themselves' etc. Carers tend to ignore their own health and have no time to visit doctor which can then have an adverse effect on the health and well-being of those people for whom they are caring. When the Cared for person dies or moves to a different service provision, the carer often loses both their role and structure to their day.

**Outcome to achieve:** To ensure that all carers can access the services that are provided.

**Goals:**

- To produce and provide Carer Awareness Training programme for those supporting carers by 2017.
- Promote and raise awareness of Young Carers across Children's Services
- To continue promoting services that will support the health of carers

## 10.6 To be recognised and valued as an equal partner in care

One of the key areas for carers is to be considered a partner in the service being provided, as they

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are playing a key role in this and benefit greatly if it is considered to be a partnership approach.

**Current position:** There is a carer on the Shetland Carers Strategy Group, two carers annually invited to attend the Carers Parliament. Carers are part of health and social care community plans. The recent Draft Carers Charter for Scotland gives national recognition to the right of carers to choose the level of care they can provide for the cared-for person. In Shetland there are now more Carer Support Plans in place and the integration of health and social work teams has resulted in more awareness of the need to plan with the carer and the cared-for person.

**Issues to overcome:** A lot of carers do not have time to commit to strategic roles as they are often too busy with their caring role to participate, other options need to be explored for how they can contribute to these processes. Carers do not always feel that they are given the opportunity to choose level of care provided and assumptions are sometimes made by professionals regarding the level of support available from carers. Some carers feel that support workers don't provide the same quality care as they can themselves, some carers can feel excluded from communication between professionals and cared-for person, especially Young Carers, also some Health and Social Care professionals fail to recognise that the carer may be the expert in understanding the needs of their cared-for person.

**Outcome to achieve:** All carers have the right to choose level of care that they provide in a partnership approach with Services and all carers are involved in the Support Plan of cared-for person

### Goals

- Promote involvement and consultation with carers in all strategic groups
- Promote partnership involvement through the WYFY process
- Promote use of carer support plans



## **11 Putting the Carer's Strategy into practice**

### **11.1 Carers Strategy Implementation Plan**

This Carers Strategy Implementation Plan looks at the outcomes for Carers in the Carer Support Plan, and links these with the Carers Strategy proposals, to outline a programme of action. The Shetland Carers Strategy Group will be responsible for ensuring the implementation plan is auctioned and updated.

## Appendix 1: Carers in Shetland– the 2011 Census

<b>People providing Unpaid Care</b>	<b>Percentage of population</b>	<b>No. of people</b>
% Providing 1 to 19 hours of care a week	5.8	1344
% Providing 20 to 34 hours of care a week	0.6	139
% Providing 35 to 49 hours of care a week	0.5	116
% Providing 50 or more hours of care a week	1.9	440
<b>Additional information:</b>	<b>Percentage</b>	<b>No. of people</b>
% Carers who are female	<b>58.2</b>	<b>1184</b>
<b>% Carers who are employed (excluding full-time students)</b>	<b>67.6</b>	<b>1375</b>
% Carers aged under 16	<b>1.6</b>	<b>33</b>
<b>% Carers aged 65 and over</b>	<b>17.4</b>	<b>354</b>
% Households with one or more carers resident (Total number of households with residents in Shetland is 9950)	<b>15.3</b>	<b>1522 households</b>

In terms of self-reporting, the **2011 census** shows **2034** people who identify themselves as carers. The following table provides more detail of this:

Source: Scotland's Census 2011 <http://www.scotlandscensus.gov.uk/ods-web/area.html#!>

## Appendix 2 Benefits Advice and Information

Type of Issue	2014 to 2015 (12 months)	April 2015 to July 2015 (4 months)
Queries about Carer's Allowance	114	42
Health related carer queries (includes queries about carer's assessments, respite care queries, non-NHS concerns/complaints and other related issues)	122	58
Queries about community care	585	109
Queries about community care charges assessments	4	5
Mental capacity issues (PoA, Guardianship Order)	46	20

## Appendix 3 - Funding and resources

The funding specifically allocated to carers through the Carers Information Strategy money is shown in the table below, marked with \*. There are other allocated funds that are held within other services or which support carers and are also shown below:

<b>Funding</b>	<b>£'000s 15/16</b>
Respite care at home e.g. Shetland Care Attendant Scheme	87
Advocacy Scheme for Carers	13
Workforce Development	6 *
Carers Training, incl. Attendance at national events	3 *
Support for Carers Groups/ Outings/ Transport	5 *
Administration: Newsletters	1 *
Carers Helpline (CAB)	1 *
Support & Advice	11 *
Day services for older people	647
Short Break Provision inc. day time only breaks	702
Supported Vocational Activity (EGRC) for people with learning disabilities	1469
Short break services for children with disabilities	1043
Supported employment opportunities	312
<b>Total</b>	<b>4152</b>

## Appendix 4: Linking to Carer Support plan and strategy

EPiC Aim	Carer Strategy Proposal	Carer Support Plan Outcome
To be identified	<ul style="list-style-type: none"> <li>▪ Recognising carers</li> <li>▪ Carer Awareness Training</li> <li>▪ Information and support for carers</li> </ul>	<ul style="list-style-type: none"> <li>▪ Informed about my caring role</li> </ul>
To be supported and empowered to manage my caring role	<ul style="list-style-type: none"> <li>▪ General Carer Support</li> <li>▪ Training for Carer</li> <li>▪ Carers Support Plan</li> <li>▪ Carer Advocacy</li> <li>▪ Emergency Planning</li> <li>▪ Carers in workforce</li> </ul>	<ul style="list-style-type: none"> <li>▪ Confident in Caring</li> <li>▪ Healthy and well</li> <li>▪ Appropriate work and caring role balance</li> </ul>
To be enabled to have a life outside caring	<ul style="list-style-type: none"> <li>▪ Respite/ Short Breaks</li> <li>▪ Self Directed Support</li> <li>▪ Benefits Advice and Information</li> <li>▪ Work/Life Balance</li> </ul>	<ul style="list-style-type: none"> <li>▪ Appropriate Work and caring role balance</li> <li>▪ Appropriate Work, education, training &amp; caring role balance</li> <li>▪ Appropriate Social Life and caring role balance</li> </ul>
To be fully engaged in the planning and shaping of services	<ul style="list-style-type: none"> <li>▪ Involve Carers in Carer Awareness Training</li> <li>▪ Gather Feedback from Carers</li> <li>▪ Involvement in strategic planning and improvement groups</li> </ul>	<ul style="list-style-type: none"> <li>▪ Confident in ability as a partner to shape services</li> </ul>
To be free from disadvantage or discrimination related to their caring role	<ul style="list-style-type: none"> <li>▪ Carers' Own Health</li> <li>▪ Remote and Rural issues</li> <li>▪ End of caring</li> <li>▪ Poverty</li> <li>▪ Carers as a diverse group</li> <li>▪ Employability</li> <li>▪ Young Carers Transition to Adult Services</li> </ul>	<ul style="list-style-type: none"> <li>▪ Healthy and well</li> <li>▪ Confident in dealing with changing relationship</li> <li>▪ Free from financial hardship</li> <li>▪ Appropriate work, education, training &amp; caring role balance</li> </ul>
To be recognised and valued as equal partners in care	<ul style="list-style-type: none"> <li>▪ Right to choose level of care</li> <li>▪ Involved in cared-for person's support plan</li> <li>▪ Partnership</li> </ul>	<ul style="list-style-type: none"> <li>▪ Confident in Caring</li> <li>▪ Confident in ability as a partner to shape services</li> </ul>