



Shetland Islands Council

# **Carer Information Strategy**

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## Executive Summary

Recent research emphasises the need for good information and advice services as part of a range of resources and supports for carers.

The aim of the Carer Information Strategy is to provide better support for unpaid/family carers to enable them to continue in their caring role for as long as they are willing and able to do so, by identifying carers at an early stage and at any point of contact with NHS Shetland or the Council and providing them with the information and advice they need.

The Scottish Executive has issued guidance on the production of Carer Information Strategies for the NHS. NHS Shetland and Shetland Islands Council have worked together to produce a Joint Carer Information strategy for Shetland.

The Strategy states the principles adopted by both agencies when working to support carers. These reflect the specific needs of young carers (aged under 16) and carers from black and minority ethnic groups.

Areas for future service developments have been identified and include ideas for new information materials such as information packs for care at home services or residential care; displays in public places; "Quick Guides" to services; an interactive web site for carers; videos and audio tapes.

The strategy highlights the need for early identification of carers. Key posts are identified within NHS Shetland and the Council to act as Carer Identification Officers with responsibility within their area of work for carer identification and the promotion of information to carers, in particular their potential right to an assessment of their needs as a carer.

Carer awareness training for staff from the statutory agencies and independent sector will be developed and included in staff induction training.

A training programme for carers will be developed and cover topics such as moving and assisting, medication, stress management and benefits advice.

Shetland's Single Shared Assessment has a section devoted to carers' assessments and Joint Future Local Improvement Targets for 2004/05 include carers' assessments as a priority.

The Carer Information Strategy complements and should be read alongside the Shetland Young Carers' Strategy and Carers' Strategy.

## Introduction

Scottish Ministers now require all NHS Boards by 31 March 2005 to prepare and submit to them for approval a “Carer Information Strategy”.

This is Shetland’s first Carer Information Strategy. It has been prepared jointly by NHS Shetland and Shetland Islands Council as part of the implementation of the Joint Future Agenda locally.

The Strategy will enable NHS Shetland to:

- Meet the 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
- 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.<sup>1</sup>

## Objectives

Carers are identified at an early stage and at any point of contact with NHS Shetland or the Council and provided with the information and advice they need.

The specific information needs of young carers (aged under 16), of older carers and of carers from black and minority ethnic groups are met appropriately.

Carers are supported so that they can continue to perform their caring role for as much and as long as they are willing and able to do so.

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<sup>1</sup> NHS Shetland is the generic name for Shetland NHS Board

## Consultation

The strategy was circulated for comment in draft form to a number stakeholder groups. These included:-

- Voluntary Sector Organisations
- NHS 100
- PFPI (Patient Focus Public Involvement) Steering Group
- Older People's Strategy Group
- Social Forum of Shetland Islands Council

All comments received by 31 March 2005 have been considered in finalising the strategy.

Further work on developing the strategy will take place during the summer of 2005 and an update report will be prepared in October 2005.

The Carers' Strategy and Young Carers' Strategy will also be updated and an executive summary covering all three strategy documents will be produced.

## Background

There are 660,000 unpaid carers in Scotland<sup>2</sup>. Shared Care Scotland in their newsletter for January 2005 draw attention to research which demonstrates that unpaid carers are more likely to have health problems than non-carers and that this can be attributed in part to a lack of information and support<sup>3</sup>.

### **Information Needs**

Service users and carers need information to:

- Understand their health and care needs
- Know what services are available to them
- Participate fully and effectively in assessments of care needs and reviews
- Access and use care services appropriately
- Participate in the delivery of care
- Complain about services if they are unhappy about the care they receive
- Access other related services such as benefits advice

### **Work done previously in Shetland**

In 1999, NHS Shetland and the Council completed a review of information available to service users and their carers. Staff worked with a carers' representative nominated through Shetland Voluntary Care Forum to produce a report which made a number of recommendations. These included:

- Review of existing leaflets
- Better systems for distributing leaflets ensuring up to date copies were on display
- Developing new leaflets based on care group sections in the Joint Community Care Plan 2000-2003.
- Developing a web-site for social work incorporating links to other agencies web-sites including voluntary sector organisations operating in the care sector.

Other work on the information needs of service users and carers has been undertaken more recently through the PFPI initiative.

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<sup>2</sup> 2001 Census

<sup>3</sup> Shared Care Scotland News, January 2005

## Policy Framework

### **Nationally**

This strategy has been developed within the context of national developments and legislation affecting carers. Key national policy documents and legislation include:

- Adults with Incapacity (Scotland) Act 2000
- Carers (Recognition and Services) Act 1995
- Children (Scotland) Act 1995
- Community Care and Health (Scotland) Act 2002
- Fair For All, 2002
- Mental Health (Care & Treatment) (Scotland) Act 2003
- NHS & Community Care Act 1990
- Race Relations Amendment Act 2002
- Scotland's Health White Paper "Partnership for Care" 2003
- Strategy for Carers in Scotland 1999

### **Locally**

The Carer Information Strategy complements and should be read alongside Shetland's Joint Carers' Strategy, Shetland's Health & Community Care Plan and Shetland's Young Carers' Strategy. These contain additional information relating to the services available to support carers locally and service developments planned for the future.

The **Young Carers' Strategy** identifies a number of objectives and planned actions to achieve these under the following headings:

- Identifying young carers and assessing their needs
- Reaching full potential
- Encouraging good physical and mental health
- Allowing choice and control for young carers

Shetland's **Joint Future Local Partnership Agreement** sets out joint management and resourcing arrangements for Joint Future services including services for carers. Service developments are initiated and progressed through the Joint Future management framework, which is an integral part of the CHP and is set out in the Scheme of Establishment for the CHP.

**Race Equality Schemes** for NHS Shetland and the Council have been developed co-operatively under the auspices of the Community Planning Board and the principles are reflected in this strategy.

## Definitions

“A **carer** is generally defined as a person of any age who provides unpaid help and support to a relative, friend or neighbour who cannot manage to live without the carer’s help due to frailty, illness, disability or addiction. The support a carer provides may include moving and handling, help with feeding, personal hygiene and administering medication as well as providing emotional support, acting as an advocate or guardian for the cared-for person and enabling the person with support needs to access leisure and recreation.”<sup>4</sup>

**Adult Carers** are recognised by the Scottish Executive as “**key partners** in providing care”<sup>5</sup> with local authorities, the NHS and other support agencies.

**Young Carers** i.e. carers aged under 16, are recognised as a distinct group with specific needs. There is a multi-agency Young Carers’ Strategy for Shetland that has been developed by the Children and Young People’s Services Planning Group. Specifically all agencies are committed to ensuring that a child does not have a level of caring responsibilities that may undermine their ability to participate in education, leisure or social activities.

Carers have a **right to an assessment** to establish their “ability to provide or continue to provide care” for another person<sup>3</sup>. Assessments for carers are an integral part of the Single Shared Assessment process and are available to anyone who provides “a substantial amount of care on a regular basis”.

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<sup>4</sup> Introduction of NHS Carer Information Strategies Draft Guidance – August 2004

<sup>5</sup> Community Care and Health (Scotland) Act 2002

## Principles

- **Adult carers will be recognised and treated as key partners in the provision of care.**

This means that:

- Carers knowledge and expertise will be taken into account to ensure the cared-for person receives services that are right for their needs.
- NHS and local authority staff will share information equally with carers provided the cared-for person has given their consent.

- **Young Carers under the age of 16 will be recognised first and foremost as children.**

This means that:

- Young carers will be supported so that their caring role does not have an adverse affect on their own social, leisure and educational opportunities.
- Young carers will not have a greater caring role than they want.
- Young carers will be informed of their right and eligibility for an appropriate assessment.
- Staff in the NHS and the local authority will be sensitive to possible tensions between young carers and their parents/guardians.

- **Older carers will be supported to enable them to fulfil their caring role for as much and as long as they wish and are able to care.**

This means that:

- NHS and Council staff recognise that caring is likely to demand more of an older carer.
- NHS and Council staff will focus on the impact of the caring role on the individual carer.

- **All carers will have access to information, advice and guidance in a format appropriate to their needs.**

This means that:

- General information will be made available in formats and languages that are accessible to, for example, young carers, carers with learning disabilities or sensory impairment, older carers and carers from black and minority ethnic groups.
- Carers will be identified through the assessment process and specific information relevant to their own circumstances will be made available and accessible to them as appropriate.
- Carers will be advised of NHS and Council complaints procedures.
- Staff will understand the needs of carers and having the knowledge to meet carers' needs for appropriate information and advice.

- **All carers will be treated equally and will be able to access services to meet their needs irrespective of their race, religion/faith, sexual orientation, age, disability or gender.**

- **Carers from black and minority ethnic groups will be recognised and supported in accordance with the requirement of the Race Relations (Amendment) Act 2000 and NHS responsibilities under "Fair for All".**

This means that:

- Staff in NHS and the Council will recognise the effects of discriminatory behaviour and eliminate discriminatory practices affecting carers.
- Staff will value diversity and demonstrate this through appropriate communication styles, attitudes and behaviour.

- **Carers of people with a mental disorder as defined by the Mental Health (Care & Treatment) (Scotland) Act 2003 will be recognised and supported in ways appropriate to their specific needs.**

This means that:

- Carers will be given information that is appropriate to their caring role with the cared-for person. This may include information about the types of disorder, medical condition, medication, treatment and practical issues relevant to their circumstances.
  - Where service users are unable to consent through incapacity and there is no formal arrangements already in place to support them, NHS and Council staff will work together with the nearest relatives and consider what action may need to be taken under the Adults with Incapacity (Scotland) Act 2000.
- **Staff at all levels of NHS Shetland and in the Council will work in partnership with a wide range of stakeholders to promote the needs of carers.**

This means:

- Working in partnership with carers themselves in line with “Partnership for Care”
- Working with other agencies through the Community Planning Board and the Community Health Partnership on planning for the future.
- Working jointly with carers and others on health improvement and well-being.

# Roles and Responsibilities

**Lead Officer**

The Lead Officer for NHS Shetland with responsibility for the effective development and implementation of the Carer Information Strategy is the Director of Patient Services (DPS). The DPS reports directly to the Chief Executive and sits on the Senior Management Team.

**Patient Focus and Public Involvement Initiative**

The Lead Officer for the Patient Focus and Public Involvement Initiative locally is the Assistant Director of Patient Services (ADPS) who reports directly to the DPS.

Through PFPI locally carers will take part in focus group activities on a range of topics and contribute to reviews of policies and procedures including:

- Discharge Protocol
- Complaints procedures
- Information availability / accessibility
- Sign posting
- Key workers / named nurse role in providing information and advice

**Carer Identification Officers**

The post holders identified below will be responsible within their area of work for the promotion of information to carers and for carer identification.

GP practices	CHP General Manager
Community Nursing Teams	CHP Lead Nurse
Gilbert Bain Hospital	ADPS Nursing
Montfield Hospital	Chief Pharmacist
Hospital and Community Pharmacist	Senior CPN (Community Psychiatric Nurse)
Community Mental Health Team	Children’s & Young People’s CPN
Children & Young Peoples Mental Health Team	
Therapy Services	ADPS
Community Care and Joint Future Services	Community Care Manager

### **Human Resources Managers**

The HR Manager for NHS Shetland and the Personnel Manager for the Council will be responsible for the development and promotion of carer-friendly employment policies. These will be in addition to and complement existing family friendly policies.

### **Training Managers**

Induction programmes will be reviewed as part of the implementation of the Carer Information Strategy to ensure all staff are aware of the need to identify carers at an early stage.

### **Line Managers/Supervisors**

All staff with supervisory responsibilities will be aware of and responsive to the needs of employees who are carers. Employees should have the opportunity to discuss any issues they have in their roles as carers confidentially in supervision or with the staff welfare officer/personnel section.

## **Carer Identification & Assessment Process**

### **Information Sharing**

There is an Information Sharing Protocol jointly agreed by the Council and NHS Shetland. The protocol underpins the Single Shared Assessment and all joint working across agencies.

Information is shared on a case by case basis subject to the agreement of the service user that information about them can be shared.

Aggregated Information is also shared and published by the Council and NHS Shetland to inform planning processes.

### **Hospital Discharge**

The Discharge Liaison Nurse and Health Service Liaison Social Worker will each have a key role in ensuring effective carer identification and carers assessment where appropriate prior to discharge.

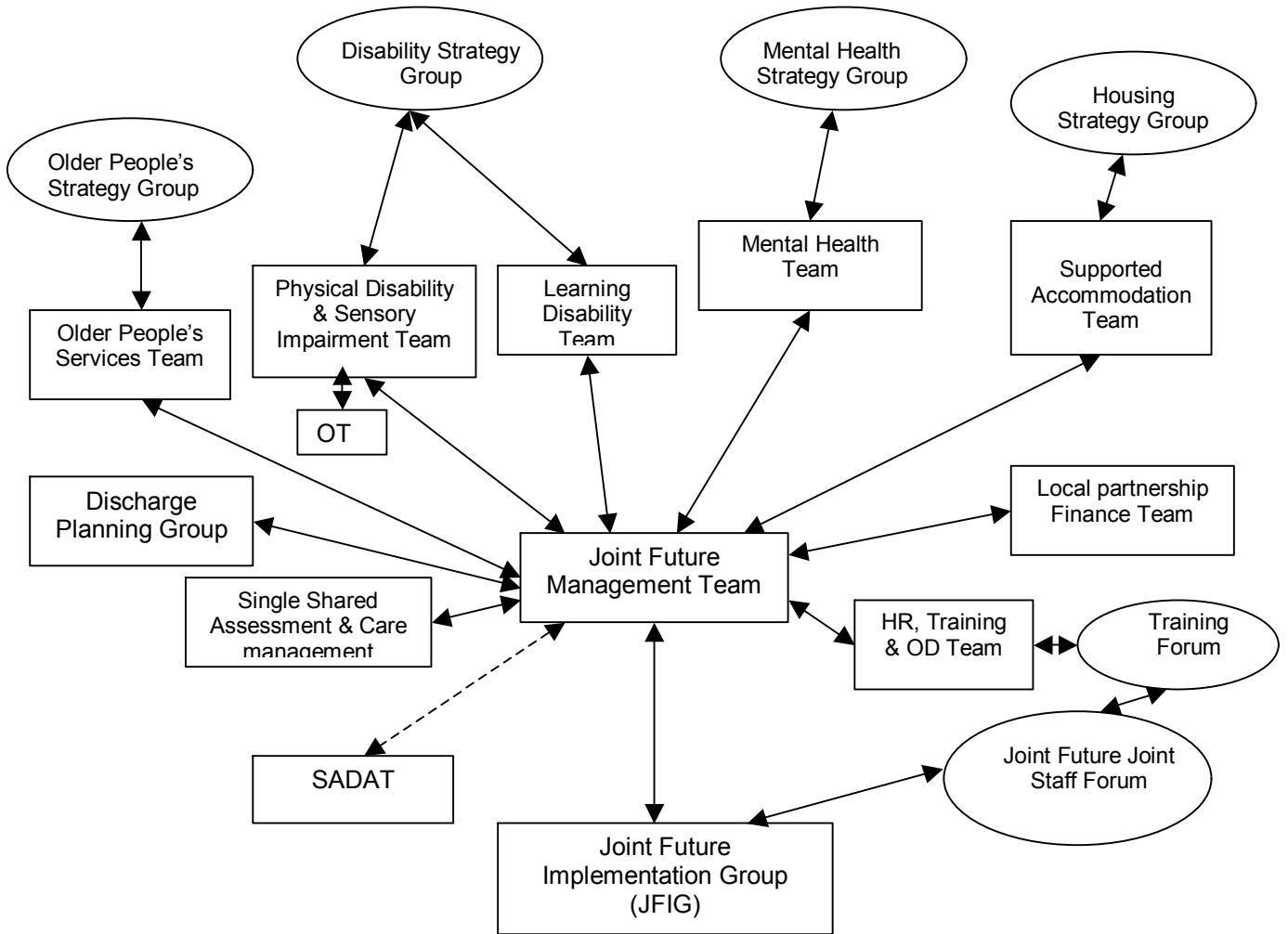
Both post holders will work together to ensure carers' issues are taken into account fully during discharge planning. They will ensure that specific information is made available to carers in a format that is accessible to them and relevant to their particular circumstances, including signposting other resources which may be useful.

# Partnership Working

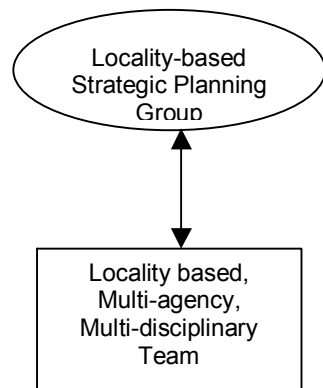
## **CHP and Joint Future**

The Scheme of Establishment of the CHP locally incorporates Joint Future planning and management arrangements. These are shown in the diagrams below:

### Specialist Services



### Generic Services



10; one for each local health centre area.

Service users and carers are represented on the strategic planning groups and on each Public Partnership Forum (PPF). There will be a PPF for each of the ten localities in Shetland based on health centre areas.

One of the main roles of each PPF is “to engage local service users, carers and the public in discussions about how to improve services to enable the CHP to respond to the needs, concerns and experiences of patients, carers and families”.

Carers service developments are promoted by the Joint Future Management Team which brings together lead officers from all specialist care groups and HR and finance specialists in a functional management relationship across the NHS and Council.

This group will be responsible for monitoring progress against the objectives of the Carer Information Strategy and Joint Carers Strategy advising the NHS Board via the CHP.

### **Integrated Children’s Services Planning Group (ICSPG)**

The ICSPG draws together a wide range of professionals from the statutory and voluntary sector. The group has developed a Young Carers’ Strategy and promotes the identification of and provision of information and resources to support young carers through all staff who come into contact with children and young people including health professionals, teachers, youth workers, social workers.

The ICSPG will link into the CHP. The development of the Integrated Children’s Service Plan will draw together all aspects of planning for children’s services including the needs of young carers.

### **Voluntary Sector**

Shetland Council for Social Services (SCSS) has a key role in representing the views of service users and particularly their carers through the Voluntary and Independent Sector Partnership (VISP). This links directly to the Community Planning Board.

## Information and Advice Services

### **Current Service Provision**

The Council and NHS Shetland routinely produce a wide range of information on the services available from the statutory agencies and voluntary sector organisations. Information is made available in the following ways:

- **Booklets / Fact sheets** – NHS Shetland provide booklets / fact sheets on specific conditions, illnesses and treatments. These include advice to all patients and their carers on discharge from hospital.
- **Leaflets** – are available on all community care service provision in different languages and Braille or audio on request, including leaflets for carers or young carers giving information on the right to an assessment and a range of useful contacts.
- **Websites** – the Council and NHS Shetland websites provide up to date information on all services and contact information. Further work is needed to develop interactive sessions and use the internet to consult carers and the public on needs. A recent exercise by the Community Planning Board locally to ask for views looking to the future<sup>6</sup> was very successful with over three thousand people responding on-line.
- **Local Area Co-ordinator (LAC)** – The Council employs a full time Local Area Co-ordinator. The LAC provides information and advice to people of any age who have a learning disability, their family and carers. The LAC acts as a link worker across agencies to help sign post resources and support services available.
- **Single Shared Assessment (SSA)** – Carers are identified as part of every SSA and on referral for an assessment. Referral forms and the SSA prompt for identification of carers and whether or not a carer's assessment is required/requested.
- **Carers Assessment** – Carers who provide a “substantial amount of care on a regular basis” are entitled to an assessment of their needs as a carer in their own right. There is a separate section in the SSA process that focuses on the needs of carers. Training on carers assessment is an integral part of multi disciplinary training on the SSA which is available to a wide range of professionals in the NHS, the Council and voluntary sector. CareNap D is used to provide additional information for people with dementia and their carers.

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<sup>6</sup> The Long Range Forecast

- **Voluntary Sector Organisations** – the Council and NHS Shetland work in partnership with a number of organisations in the voluntary sector providing information on the services they provide and who to contact. These include:

Advocacy Shetland	Diabetes UK	Disability Shetland
Alcohol Advice Centre	The Samaritans	MS Society
Red Cross	Shetland Autism Support	Shetland Link-up
Shetland Parents Support Group	Arthritis Care	Age Concern
SWRI	Shetland Council of Social Services (SCSS)	League of Friends
British Heart Foundation	Shetland Crossroads Care Attendant Scheme	Shetland Club for the Deaf and Hard or Hearing
Special Needs Action Group (SNAG)	Shetland Youth Information Service	Cancer Care
Breast Cancer Support Group	Care for Unst	SHOARD
Shetland Citizens Advice Bureau (CAB)	Shetland Childminders Group	Life (Shetland)
Shetland Womens Aid	Stepping Stones Club	Couple Counselling
Assoc. of Shetland Pre-School Play	Befriending Scheme	Moving On
Voluntary Services Resource Centre	Firth & Mossbank Family Centre	C.O.P.E Ltd
Shetland Stroke Support Group	Shetland Hospitals and Community Friends	Epilepsy Shetland
WRVS	Shetland Community Drugs Team	

- **Shetland Citizens Advice Bureau** offers free, confidential advice to any member of the public. They also operate a **Welfare Rights Service** with funding from Shetland Charitable Trust.  
Future plans include the development of a **Direct Payments Support Service** at CAB commissioned by the Council.
- **Voluntary Resource Centre** - Many other local voluntary organisations provide information, advice and support to carers. In June 2005, SCSS will open a new Voluntary Resource Centre in Lerwick bringing together many local voluntary organisations under one roof. NHS Shetland and the Council will work closely with SCSS to ensure that a comprehensive range of materials is available to service users and carers at the new centre.
- **Independent Advocacy Services** - NHS Shetland and the Council jointly commission a range of independent advocacy services. These include:
  - Generic advocacy service for all users of health and social services
  - Carers' advocacy specifically for unpaid unpaid/family carers.

- Specialist mental health advocacy services to meet the needs for advocacy of people with a mental health disorder as defined by the Mental Health (Care & Treatment (Scotland) Act 2003.

- **Counselling Services**

Counselling services are available through each of the 10 GP Practices across Shetland. Some voluntary sector organisations also provide counselling from COSCA trained counsellors. These include:

- Alcohol Resource Centre
- Shetland Community Drugs Team
- Women's Aid
- Shetland Link Up
- Shetland Youth Information Service (SYIS)

## **Future Developments**

Ideas for additional information resources include:

- Using audio-visual formats e.g. videos, audio tapes.
- "Quick guides" to services
- Laminated cards with key contact details
- Information packs including
  - Discharge pack
  - Care at home pack
  - Residential care packThese would complement the "Helping Hands" pack prepared by Disability Shetland for families with a child or young person with disabilities.
- Displays in public places

## Training

### **For Carers**

Shetland's Joint Future Joint OD and Training Plan includes courses developed specifically for carers covering the following topics:

- Moving and assisting
- Benefits advice
- Stress management
- Administering medication
- Dementia
- Challenging behaviour

Carers can also access funding via the Social Work service to cover reasonable travel and accommodation costs and course fees for specialist training courses in mainland Scotland on care for specific conditions.

### **For Staff**

Carers issues will be included in induction programmes for all frontline staff / practitioners and will cover carers potential entitlement to an assessment, identification of carers and diversity /equality issues.

Multi-agency training in Single Shared Assessment Procedures will cover the carer's assessment. SSA training is available to a wide range of professionals including community and hospital nursing staff, GPs, social workers, occupational therapists, physiotherapists.

Diversity training is a key priority for all NHS staff.

### **For Voluntary Sector Staff and Volunteers**

Training opportunities will be made available to staff in the voluntary sector and to volunteers to support them in their work with cares.

## Funding

Many of the costs of providing information and advice services are included in other service budgets. The main sources of funding for services that include a focus on information and advice for carers that can be identified separately are indicated below.

The figures shown are for 2005/06 and are expected to be annually recurring unless otherwise stated.

### **NHS Shetland**

TBA<sup>7</sup>

### **Shetland Islands Council**

Public Information e.g. leaflets.	£8,050
Training for carers	£2,500*
Local Area Co-ordinator	£29,940
Direct Payments	
- Support Service (from 2005-06)	£12,000
- One off start-up costs	£ 2,500
Independent Advocacy	£15,000

\* Training opportunities are available for carers organised by the Council and NHS Shetland for which the funding is not identified here. A Joint Training and OD Plan is available separately

### **Shetland Charitable Trust**

Welfare Rights Service	£ 34,000
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<sup>7</sup> To Be Advised

## Action Plan

Task	Timescale	Lead Officer / Agency
Review public information with carers in mind	On-going	Snr Planning & Information Officer, SIC/NHS
Increase amount of information available on websites	On-going	Assistant Director of Patient Services / Clinical Governance Support Team
Develop interactive website for carers	2005/06	Snr Planning & Information Officer, SIC/NHS
Develop on-line carers support network	2005/06	TBA
Formalise distribution processes for information on services to ensure up-to-date versions are available in all locations e.g. GP surgeries, hospital wards, Council offices, websites, voluntary sector organisations, social care settings.	By Sept 05	Snr Planning & Information Officer, SIC/NHS
Revise Discharge Protocols to include explicit reference to the identification of carers and their right to an assessment of need.	By July 05	Snr Planning & Information Officer, SIC/NHS
Publicise training plans for carers and include training for staff on carers issues in Joint OD and Training Plans.	By April 05	Training Manager, SIC Social Work Service
Develop training programmes for carers including moving & handling, benefits advice, stress management, administering medication and challenging behaviour.	By April 05	Training Manager, SIC Social Work Service
Promote carers issues via GP surgeries and Primary Care staff <ul style="list-style-type: none"> <li>➤ Include carers issues in training for all staff including receptionists</li> <li>➤ Provide literature for patients and their carers e.g. leaflets, fact sheets</li> <li>➤ Develop health promotion libraries at health centres for patients and their carers</li> <li>➤ Publicise contact details for carers services, information and advice</li> <li>➤ Ensure monitoring mechanisms for new GMS contract. Organisational Quality Indicator 9</li> <li>➤ Develop the role of community and</li> </ul>	2005/06	CHP General Manager

GP practice nurses in identifying and supporting carers		
Promote carers issues via community pharmacists ➤ Ensure community pharmacists have a range of up-to-date information available for carers e.g. sign posting ➤ Develop community pharmacists role in identifying and supporting carers	2005/06	Chief Pharmacist
Publicise carers' issues through events in Carers Week 13-19 June 2005.	May 05	Director of Patient Services

Progress against the action plan will be monitored regularly by the Joint Future Management Team and reported to the Director of Patient Services and the CHP.

## Quality Framework and Monitoring Mechanisms

Specific targets and monitoring mechanisms for key deliverables are identified in the table below.

### **Information materials**

Review by PFPI group taking into account the following attributes:

- Status (formal, informal, generic, specialist etc.)
- Accessibility / availability
- Relevance
- Accuracy
- Timeliness (of availability to users / carers)
- Clarity (language, style, format) including arrangements for minority ethnic groups.
- Diversity (culturally sensitive, available in other languages)

### **Training**

- Feedback from participants (“happy” sheets)
- Numbers accessing training opportunities
- Numbers of carers from minority ethnic groups accessing training

### **Carers Identification & Assessment**

- Local Improvement Targets (LITs) for the Joint Future Agenda include targets for numbers of carers assessments completed and times for assessments from referral to completion and service provision. The LITs are reported to the Scottish Executive and published.
- Numbers of carers identified will be published locally by age and ethnic group.

### **Carers Complaints**

- Issues arising from carers’ complaints will be reported to the Joint Future Management Group and acted upon.
- All information will be made available to DPS as lead for the strategy. Information will be published with details of any action taken as a result.
- The individual carer’s right to confidentiality will be respected at all times.

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