



Orkney Carers' Strategy

2005 - 2008



The Princess Royal Trust
Orkney Carers Centre

CROSSROADS
Caring
for Carers
ORKNEY

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ORKNEY CARERS STRATEGY 2005-2008

EXECUTIVE SUMMARY

In March 2004, the Scottish Parliament's Deputy Minister with direct responsibility for Community Care, Tom McCabe, identified better support for Carers as one of four over-arching national outcomes for Community Care in Scotland.

Orkney Carers' Strategy, together with the Local Health Plan, Orkney Community Care Plan, Children's Services Plan, and the Partnership in Practice Agreement, sets out the partners' map for improvement in health, well-being and quality of life for all the people of Orkney, and for services designed to support this, including services for Carers. The Carers' Strategy also incorporates the NHS Carers Information Strategy and the Young Carers Strategy.

Carers – family members, neighbours and friends – are key service providers for adults and children with disabilities, or mental or physical health difficulties, and for frail older people. They have a personal relationship with, and a special commitment to, the person they care for; but they are not paid to provide care. Their role as partners in care provision must be recognised and supported.

Orkney Carers Strategy aims to

- Raise Carer Awareness amongst staff and management in all partner agencies
- Ensure Carers are identified and provided with accessible and useful information about services for themselves and those they care for
- Ensure Carers' rights to assessment and support of their caring role are met, including attention to their training needs and needs for respite
- Empower Carers to seek support

Objectives for service development and improvement are identified in the following areas:

- Information
- Assessment
- Short Breaks & Respite
- Hospital Admission & Discharge
- Benefits & Income Maximisation
- Employment
- The Role of the Community Social Services
- Primary Health Care
- Pharmacy
- Mental Health Services and Housing
- The needs of Parent Carers and Young Carers

The Action Plan sets targets for the responsible agencies.

The process of writing this strategy has been led by Crossroads (Orkney), with contributions from all the partner agencies identified in the document and, most importantly, from Carers themselves. It is endorsed and commended to all by Orkney Islands Council and by NHS Orkney.

ORKNEY CARERS STRATEGY

Foreword

The purpose of writing a Carers Strategy is to improve the quality of life of Carers living in Orkney and to support their vital caring role. The needs of Carers themselves for support and information may remain hidden. The importance and benefits of recognising and meeting these needs cannot be over-estimated.

The strategy will be used alongside the Orkney Community Care Plan, Local Health Plan and NHS Information for Carers Strategy. It has been compiled as a joint document with input from Statutory Services, the Voluntary Sector and, most important of all, local Carers.

The strategy is based on material drawn from a number of sources including:

- The Strategy for Carers in Scotland
- Report of the Scottish Carers Legislation working group 2001
- Community Care & Health (Scotland) Act 2002
- Scottish Executive Circular CCD2/2003 – guidance on effective implementation of all legislative provisions affecting Carers contained in the 2002 Act
- Caring About Carers – a National Strategy for Carers
- Focus on Carers and the NHS – Good Practice Guide
- Scottish Executive Health White Paper “Partnership for Care” 2003
- NHS Carers Information Strategy—Draft
- Highland Carers Strategy

The Strategy will be reviewed every 3 years, involving Carers, Carers Organisations and other Stakeholders.

Introduction

Who is a Carer? One broad definition is someone who is involved in looking after a family member, friend or neighbour, who is frail, disabled or ill. This person is unpaid unless in receipt of the Carers Allowance. Caring includes a wide range of activities beyond the purely physical, and encompasses emotional, social, psychological and financial aspects in addition to practical tending. However, many Carers do not recognise this label – they think of their role as just part of normal family relationships, friendships or neighbourliness. This means they can remain hidden from sources of help and information which could make their lives easier.

It has always been recognised that a major part of Care in the Community is provided by Carers. There are about half a million Carers in Scotland of whom 5,000 are estimated to be Young Carers under the age of 16. They represent a massive community care resource without which public services would be placed under severe pressure. They save the public purse millions of pounds each year. Their role, most often shouldered willingly, has led many to compromise their own health and well being due to not recognising the need for, as well as the lack of, sufficient support.

The 2001 Census identified 1,706 Carers in Orkney of whom 1,227 give 1-19 hours of unpaid care per week, 151 give 20-49 hours of unpaid care per week, and 327 give over 40 hours of unpaid care per week. Many work 24 hours, 7 days a week.

Legislation has developed over the past ten years to encourage support for Carers. One of the most significant pieces of strategic guidance for Scotland was issued by the Scottish Executive in 1995 – The Strategy for Carers in Scotland.

It sets out 5 main aims -

- To improve information about help and support to Carers
- To add to and improve the local services that help Carers to cope
- To introduce new laws that will help Carers
- To make sure that there are consistent national standards for the kind of short breaks that Carers need
- To check that Carers are getting the help they need

An Independent Carers Legislation Working Group was set up by the Scottish Executive in April 2001. It considered the key issues for Carers and made recommendations for new legislation. Its most fundamental observation was the need for agencies to **recognise Carers as key partners in the provision of Care**. Carers should have **equal status with other providers of care**.

Scotland's Health White Paper – Partnership for Care 2003 states:

“The vital role of Carers as major care providers must be recognised at all levels in the NHS as **partners in providing care**”.

The Community Care and Health (Scotland) Act 2002 recognises in the first of its key principles that Carers should be treated as **key partners in providing care**. Not only are they usually the main provider of care but they are unique in that they are not paid to provide that care and they have a personal relationship with and commitment to the person they care for.

We hope to avoid the situation where Carers are desperately seeking help after a crisis. However, experience of working with Carers in Orkney demonstrates that they often find it difficult to ask for help at an earlier stage in caring for the following reasons –

Carers can feel that asking for help constitutes an admission of failure to cope. This can result in lasting feelings of guilt and inadequacy

Many experienced Carers feel that only they know the person they are caring for, and that no one else will be able to substitute for them

The help offered is not always acceptable to the person they are caring for – they don't want an 'outsider in their home'

Some of the tasks people need help with do not fit in with what is available from care providers. (Things like a daily bath/shower, early morning help with rising, or late night help with going to bed)

Some Carers look on their caring role as being their duty and do not even acknowledge that they can, and should, ask for help

Accountability and Monitoring

NHS Orkney and Orkney Islands Council have always worked with partner agencies such as Crossroads (Orkney) and the Princess Royal Trust for Carers to ensure that Carers receive individualised support based on an assessment of the service user and Carers' needs. This means that although our community is small we often know and understand the needs of those Carers who require support to look after their relatives/friends. Mainstreaming of ethnic minority carer views and experiences that inform our service delivery is a routine part of our partnership approach. Orkney cannot provide everything to all people, but by taking an holistic view of Carer needs we can deliver services locally that are appropriate and ensure access to those which may be required from further afield.

2005 will see the launch of NHS Orkney's Public and Patient Partnership Forum. In keeping with the Scottish Executive's best practice guidance and the development of a Community Healthcare Partnership, NHS Orkney will utilise the forum to ensure carer and service user views and experiences are used to improve present services and plan for the future. This process will by its very nature give Carers throughout the community opportunities to contribute to the development of services irrespective of their cultural, ethnic or social background. Indeed, it is exactly this type of diversity that must be incorporated and which is important to ensuring individualised support within larger service provision.

The Action Plan set out in this Strategy will be reviewed on a yearly basis by all stakeholders. An important part of measuring our performance will be the on-going feedback from Carers themselves. This can be gathered through the Orkney Carers Centre or other services chosen by the Carer.

The whole Strategy will be reviewed on a 3 yearly basis.

The aim of this strategy is to cover all the different aspects of caring and also to recognise, use and build upon the range of services already available in Orkney.

By using the well tried format of "What do Carers feel they need?" and "How will we fulfil that need?" in each key area of Carer Support, we hope to build better ways of reaching out and helping Carers.

Information and support must be available and accessible to Carers from black/minority ethnic groups, as per the Statutory Duty placed on NHS Boards/Community Social Services Department under the Race Relations (Amendment) Act 2000, and to meet NHS responsibilities under "Fair for All".

In August 2004 the Commission for Racial Equality found that the operational policies and procedures in place within NHS Orkney were compliant with their guidance and the requirements of the Act. In particular, the delivery of equality training had been well attended by staff across the organisation.

NHS Orkney has limited access to interpretation services for Carers and service users should they require it, but this is being further developed.

Orkney Carers Strategy recognises that only by the strategy being accepted by all who care for others can we hope to help Carers – this includes Community Social Services Department staff, Doctors, Nurses and all health staff, Housing Services, Voluntary Organisations, Education Services and Employers.

In building the Strategy we need to cover key areas of Carers Support –

- Carers Needs Assessments
- Carers and the Primary Health Care Team
- Carers and Community Social Services
- Carers and Hospital Discharge Policies
- Carers and Information, Support and Advice
- Parent Carers and Educational Services
- Young Carers
- Respite Care/Short Breaks for Carers
- Carers and Mental Health and Wellbeing
- Carers and Housing
- Carers and Benefits
- Carers and Employment

The purpose of this strategy is to provide the framework to deliver the following national requirements -

To ensure that informal Carers are recognised as central in the provision of Community Care Services.

To ensure that all Carers are identified and have information at their first point of contact.

To involve all service providers in the provision of effective and targeted information and practical help to Carers in Orkney.

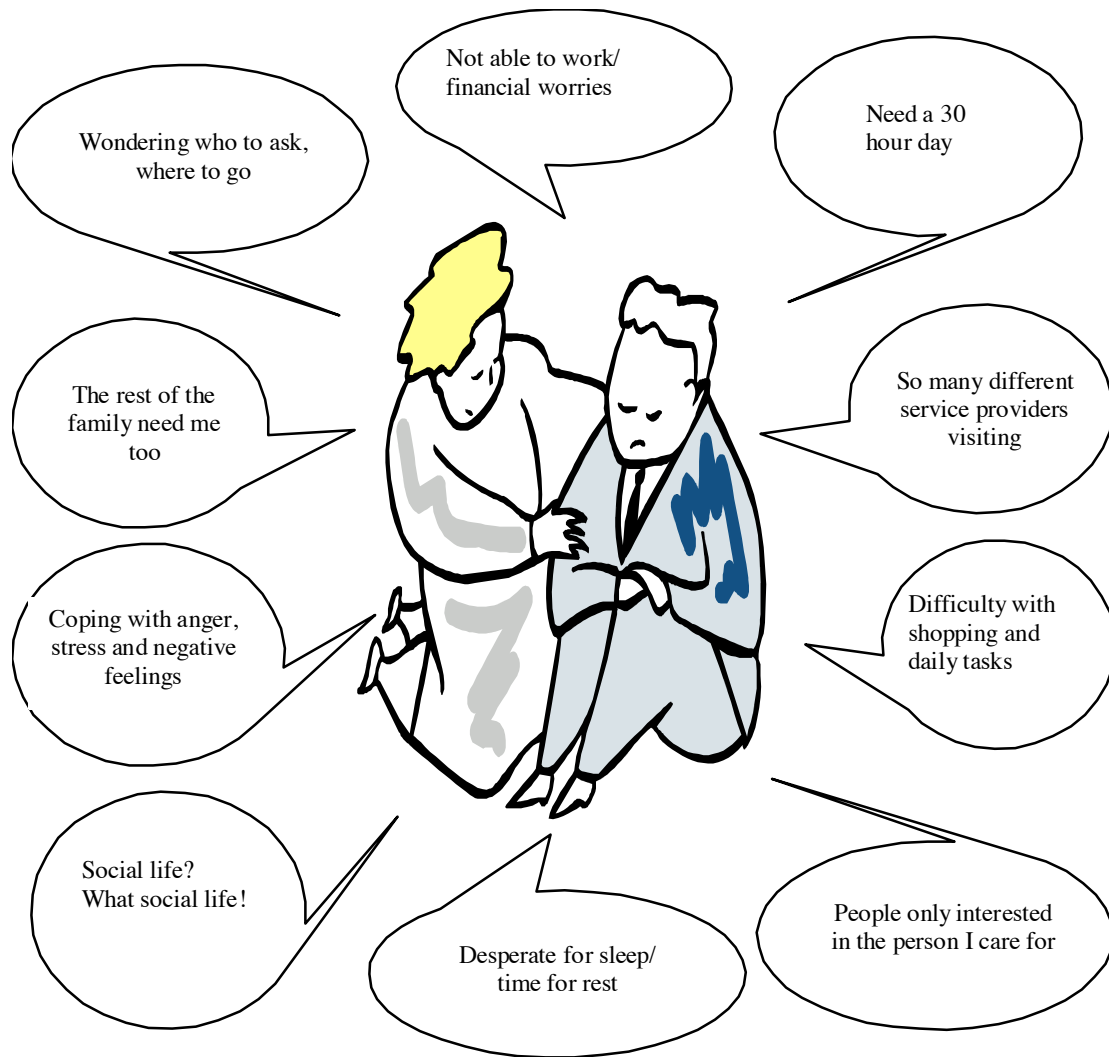
To improve the quality of life for Carers by ensuring that they receive services of a high standard on a partnership basis to enable them to continue caring.

To ensure that all Carers are informed of their right to an Independent Assessment of their support needs as a Carer.

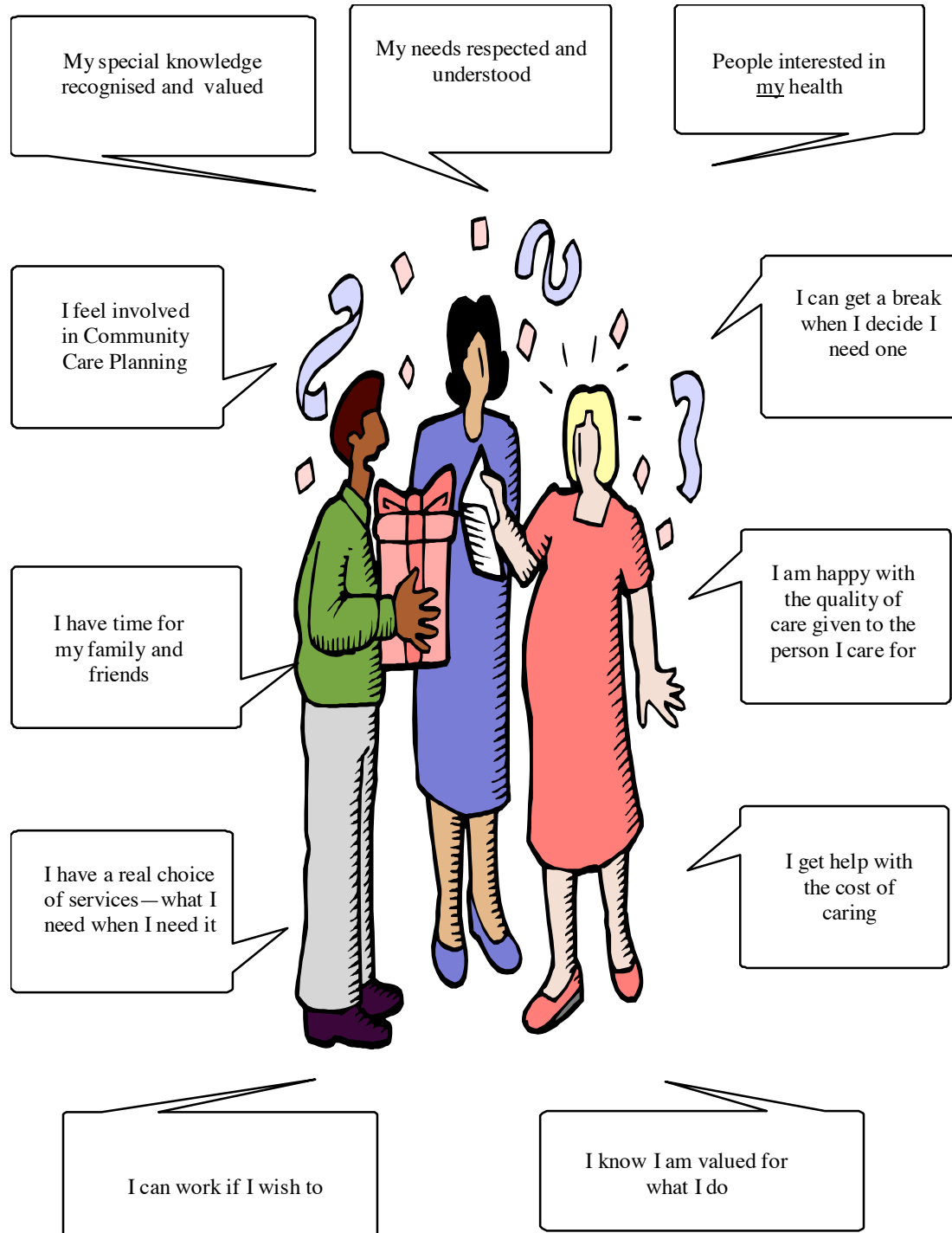
To ensure that systems are in place for Carers to be referred for appropriate support.

To develop “Carers Awareness” as a routine part of the day-to-day activities of NHS and Community Social Services staff and other service providers.

Comments from Carers without support



Comments from Carers with support



Who Was Involved in Writing The Strategy?

We tried to involve as many Stakeholders as possible by direct contact, writing to Carers and inviting (through the media) people to give us their feelings on Carers' issues. We included opinions and information from Carers themselves—through one-to-one contact, and group meetings, including sessions with Dementia Carers, and Carers of Children with Special Needs, and via a written survey. Community Social Services Department, NHS Orkney, Orkney Islands Council Housing Department, Voluntary Organisations, and the Private Sector (including Local Pharmacies) were also involved. Funding for the survey was provided by NHS Orkney. A public meeting was held to discuss the first draft.

Consultation can never be completely inclusive but we have tried to fairly represent Carers and services provided in Orkney.

Building Up The Strategy

By having a holistic view of Carers needs we can move towards having a strategy which will both fulfil needs expressed by Carers in the consultation process and ensure that all service providers are involved in helping meet these needs. The strategy looks at Carers' needs under the following headings :-

Information

Carers do not have time to search for information—they need it to be easy to understand, practical and timely. The approach of those delivering the information is as important as the information itself.

Carers and Community Social Services

Community Social Services take a lead role in the planning, assessment and provision of services for older people and people with disabilities in Orkney – recognising the expertise of, and working with, Carers will enhance their services.

Assessment

Assessments must be approached in a sensitive and skilled manner to be acceptable to Carers. These Assessments must recognise the Carers expertise and be seen to result in action which will help the Carer.

Respite Care/Short Breaks

A flexible, affordable and easily accessed respite care/short breaks service is one of the key requirements of most Carers. This has been identified nationally by Carers' Organisations (Princess Royal Trust for Carers, Crossroads (Scotland), Carers Alliance).

Primary Care Teams Partnership with Carers

Carers want to be involved in planning and delivering Health Services and they also would like their needs to be recognised too. Carers' ability to manage unsupported should not be assumed and good communication links should be established to determine how and when support is needed as well as to support carers to identify the support they would benefit from.

Hospital Admission/Discharge

The Carers' role needs to be recognised and a protocol developed to allow them to both give and receive information at the right time so as to ensure the best level of care for the patient from all those involved.

Pharmacists

This is sometimes an untapped source of Carer support especially when linked in with Primary Health Services.

Parent Carers (Parents of Children with Special Needs)

Parent Carers need to have their experiences and views sought and acted upon. All Carers should have access to the training and support required to care for their child.

Mental Health

Carers supporting someone with a Mental Health problem must be recognised as having unique needs because of the nature of the illness. Carers often find difficulty in getting support when they need it and may feel very isolated.

Housing

Carers need a suitable environment to care for their relative/friend, therefore - access to better quality housing and advice on how to improve their housing circumstances is essential whilst recognising each individual's rights to live where they feel is adequate and not have it dictated by professionals.

Benefits/Income Maximisation

Raising awareness among Carers of the range of the financial help which is available should be a priority among both the Statutory and Voluntary Sector Organisations.

Carers in Employment

Juggling work and caring is an extremely complex process many Carers have to live through. Employers and respite care/short break providers need to recognise this need and work towards developing a flexible approach to helping support Carers who wish to/need to work.

Young Carers – The Strategy for Young Carers – Appendix A

Issues affecting Young Carers need to be raised within Education Service Providers and families themselves. Work with Young Carers needs to cover the social/fun side of life as well as emotional and educational issues.

INFORMATION AND TRAINING

The provision of accurate and accessible information about services/benefits available to Carers is crucial in supporting Carers in their caring role is one of the five main aims in the Strategy for Carers in Scotland. Carers continually refer to the problem of not knowing what questions to ask or who to ask. Each Carer will have different needs and abilities and the information must be presented with this in mind.

The draft NHS Carer Information Strategy states that the Executive is committed to ensuring that all Carers have access to targeted information that helps to support them in their caring role, and to make that information available as early as possible. It also states that the NHS has a vital role to play in identifying Carers, offering them information and referring them on to a source of advice and support.

Recent work with the Scottish Consumer Council has also resulted in the publication and distribution of Carer and Service User information booklets on Accessing Health Records and ensuring patient confidentiality. Both of these booklets are available in large print, braille and other languages should a Carer or Service User require the information.

In our survey only 67% of Carers felt that they had enough information about services available to Carers in Orkney. 46% of Carers said they would prefer this information in writing, 36% by word of mouth from a professional visiting and 10% thought a phone call sufficient. Very few thought the Internet a possibility.

“I have difficulty in knowing who to approach for help—it feels like a maze with no map”

“I have had helpful, supportive talks with Crossroads (Orkney) and Advocacy”

The value of the “Information for Carers” booklet is recognised by Carers as a starting point for guiding them to services and benefits available in Orkney.

For Carers to feel confident and supported in their role, which sometimes involves dealing with relatives with a high level of disability, they need access to appropriate training.

“Training is especially important when lifting is involved—it is not enough to be told what you are doing wrong, and then left to do it.”

A staggering 93% of Carers who completed our survey stated that no one had asked if they would like training on how to care for their relative/friend. However some reported that they had been offered and/or received the training from either their community nurse or another source as time went on which was very welcome. It is recognised however that in many situations people become Carers gradually over a period of time and their training needs are not recognised.

Recognition is needed of the wide ranging beliefs, lifestyles and cultural backgrounds of the people of Orkney. Carers as well as patients have spiritual needs, and information should be made available as to where and how their needs may be met.

What do we need?

A Carers Strategy with Information for Carers highlighted as a priority.

Professional care staff to be “carer aware” and value Carers expertise and role in caring for their relative/friend.

Information on what services/benefits/help is available in Orkney at an early stage of caring. This information should be provided in a form acceptable to individual client.

To ensure Carers have access to advocacy support either through Orkney Carers Centre or Advocacy Orkney.

To ensure that Carers’ training needs are ascertained and fulfilled when they first start caring and if their dependant deteriorates.

A ‘one stop shop’ approach for Carers to ask for or explore the help they need— Carers may need to be guided to where they can access help.

Provision of general information to Carers on medical conditions, the effects of treatment, when to seek help.

Some form of identification to carry with them stating that they are a Carer and who to contact should they become ill/have an accident.

Recognition of Carers spiritual needs and provision of information about both religious and other sources of help and support.

How will we get there?

General Information and Advocacy

Regularly update the ‘Information for Carers’ booklet and ensure all Carers receive it at an early stage in caring. Orkney’s GP’s, Community Nurses and Social Work Staff play an important role in the identification of Carers and distributing the booklets. Carers could also be identified on medical notes.

Make Carers aware of other sources of information in Orkney eg. NHS 24, Health Promotion, Age Concern, targeted Internet sites, library.

Carer Awareness

Continue to support the Orkney Carers Centre as a source of information, advice and advocacy.

Develop a “Carers Identification Card”.

Include ‘carer awareness’ in staff training/induction procedures. Identify staff in NHS Orkney/Community Social Services to encourage ‘carer awareness’ – eg. at practice meetings, clinical staff meetings and Social Services Reviews etc.

Develop a *Carer friendly* approach to Carers at Customer Services in Orkney Islands Council.

Develop good communication links between patient, Carer, and professional staff involved in the patient’s care.

Ensure clarity about what information can be discussed with Carers, whilst respecting patient confidentiality and patient’s wishes. NHS Staff and Social Work Staff should actively seek patient/clients consent to be able to provide personal information to Carers.

Make Carers and patients aware of NHS Orkney’s Chaplaincy Service and Spiritual Care Policy. All service providers should be aware of the spiritual needs of Carers and those for whom they care and offer guidance as to services available.

Carer Training

As part of the ‘Discharge Protocol’ and initial approach of the Primary Care Team ensure that Carers are offered appropriate training for the task they are taking on. Carers are the ‘key’ to providing Care in the Community and need the training resources to care effectively. They may need practical training or advice on:

- a Personal care
- b Moving and handling
- c Use of hoists and other aids
- d Coping with stress
- e Information on medical conditions, effects of treatments etc.
- f Finances
- g Roles of Health and Social Care Workers and associated services

COMMUNITY SOCIAL SERVICES

Community Social Services take a lead role in the planning, assessment and provision of services for Care in the Community. They work in partnership with NHS Orkney (whose community nurses also undertake assessment and care management) and other private/voluntary providers. They also work in partnership with the many Carers in Orkney in order to enable their dependants to stay at home and are frequently the first port of call when crisis situations occur.

Carers must always be included in the assessment of the person they look after (provided consent is obtained) and their agreed contribution to the person's support should be included in the Care Plan. It is very important that Carers' willingness and ability to continue to provide help is sensitively explored, and that their own support and training needs are attended to. Assessment and Care Management should be a resource for Carers. The assessment of service users should operate at an individual and policy level and drive the whole community care process.

Specific money has been made available to Local Authorities for Carers a significant amount of which is used to fund Crossroads (Orkney) to provide Respite and Support Services, in addition to short breaks and intensive care at home in an emergency, available from Community Social Services.

Most Carers in Orkney (75%) felt that Community Social Services staff looked at their needs as well as the person they cared for. However some felt that crisis help was not always available and services were not flexible enough. Carers sometimes lack information about the resources available from Community Social Services.

“We cope if both of us are well – if either of us is confined to bed or sent to hospital the remaining person is in difficulties. – This sort of emergency never seems to be planned for by Social Workers or Doctors.”

Carers need Social Work Staff to listen to them when they are in a crisis situation and to have flexible services available to help them. The development of the Rapid Response Service can provide help in the home situation, however this does not reduce the need for crisis residential beds.

Direct Payments are now available so that people with community care needs can choose to fund and manage services for themselves. Some of those under 65 may also be eligible for Independent Living Fund monies, which can be used in tandem with provided services and Direct Payments to pay for care. For Carers this may bring benefits in terms of flexibility and control. It may also mean additional responsibilities if they are helping the person they care for to employ their own staff or buy in services. However, help is available through the Independent Living Project managed by the Orkney Carers Centre.

What do we need?

Readily available information about services available from Community Social Services in order to make a decision as to what may be helpful to themselves or the person they care for.

Recognition of Carer as an important part of the 'caring team'. Note that some Carers do not live with the person they care for.

Recognition of Carers' needs – many have nearly as many needs as the person they care for. They may need help to access services, as they cannot leave the person they are caring for.

"I know I should get a hearing aid and special phone but I have no time to attend clinics etc. so I just leave it."

Recognition of the fact that some Carers are not willing or able to continue caring for their relative/friend.

How do we get there?

Regularly update the Information for Carers Booklet and ensure it is available for Carers through Community Social Services along with other relevant leaflets/information.

Take a pro-active approach in informing Carers as to what resources are available.

The Assessment and Care Management of the person they care for should involve the Carer at all stages and their input into the person's care be recorded on the Care Plan.

If Carers have to stop caring for whatever reason they may need support through this period and help not to feel guilty about being unable to continue caring.

CARERS' ASSESSMENTS

Carers Assessments must be offered to all Carers and if they wish an assessment, a choice given as to who they would like to complete the assessment. Lead Assessors from Community Social Services, and NHS Orkney, and Orkney Carers Centre, can all undertake and complete the assessments. The function of the Carers' Assessment is to –

Acknowledge the caring role
Help Carers consider the help they provide and the needs of the person they care for
Provide an opportunity for discussion about services that are available.

Carers however have a right to privacy, and assessments will only be acceptable if approached in a sensitive, compassionate and skilled manner, acknowledging the particular expertise that Carers have.

Recent national research by the Carers National Association shows that 82% of Carers had not asked for an assessment. Carers tend to seek help when they have reached crisis point. However, in Orkney all carers who approach the Crossroads (Orkney) Scheme for respite care receive a full Carers Assessment and others are offered one by the Care Manager of the person they support, so the situation here is somewhat better than in some areas.

“as a Carer—no one looked at my needs”
“Due to my husband’s mental impairment and the fact that it is very much a hidden disability I have found it difficult to get people to understand my needs”

Carers are aware of a shortage of Care Managers especially in the Children & Families area where they are frequently assessed by ‘trainee staff’. They report the constant changes in staff difficult to deal with and need to build up relationships so they feel supported.

What do we need?

Awareness raising among Carers of their rights to an assessment/or to refuse an assessment.

Awareness raising among professionals of their responsibility and duty to offer a separate Carers Assessment as well as the Carer being part of the assessment process of the person they care for.

The assessment process to take account of all issues which identify the individual’s ability to provide care.

Revised hospital discharge procedures to take account of the training and support needs of Carers.

Recognition by Primary Care Workers, Social Workers and Hospital staff of Carers needs for training and support.

Unmet needs to be recorded and used to inform the planning process.

How will we get there?

Ensure Social Services/Health Staff/Orkney Carers Centre offer Carers an Assessment and help them complete it if required.

Include Carers' needs for training and support - identified in Assessments, and during Care Reviews.

Ensure that any unmet need is recorded and used in the planning process for Carers' Services.

SHORT BREAKS/RESPITE CARE

Moving Carers on from feeling “if I really cared about him I wouldn’t need a break” to “it is because I care for him that I need a break so that I can carry on in my role” has been the key to making Carers feel OK about accepting help.

Respite Care is the key service that nearly all Carers feel is essential. However every care situation is different and in order to provide respite, the care must be flexible and affordable. 69% Carers surveyed felt that they got enough time off from caring—they used Crossroads, Residential Respite, Day Care and help from relatives and friends.

“I am happy with the respite care I receive—I know you are there if I need more help.”

However the Carers in the outer isles were enthusiastic about the Core and Cluster model available in Hoy and Westray. Those looking after frail older relatives felt that the trip to Kirkwall/Stromness for residential respite was unfair to them and therefore did without.

Some Carers desperately needed Respite Care but their dependent was resistant—particularly common when residential respite care/short breaks was being considered.

“When my mother was trying to get out of going on respite breaks the home care agent, doctor and nurse said she didn’t need to go - no thoughts as to my needs.”
“If I didn’t have care from Crossroads and the Day Centre I would never cope.”

Others turned down offers of residential respite because they felt that there was a marked deterioration in their dependent’s mobility, and/or level of confusion when they returned home.

One recurring theme from Carers was help when they needed it.

“My respite needs depend on how much sleep I get.”
“help at short notice would be good (to go to a meeting, for a walk or out with friends.)”

Another issue, especially among parents with children with special needs, was a perceived lack of funding.

“Social Workers confuse me and are always complaining about lack of finance.”
“Residential respite for children only available to a select few.”

All Carers speak very highly of Day Care Services in Orkney and although maybe not directly counted as respite they are a lifeline to many. The one recurring request is for Day Care to be open at weekends—particularly for Carers of a relative with dementia.

“It’s a long weekend withat home all day.”

What do we need?

For Carers to be recognised as ‘providers’ of care and be given ‘time off’ from caring to enable them to be rested and enjoy other leisure/work pursuits.

Information on the range of support services available.

To be offered flexible and varied methods of providing respite/short breaks especially in the outer isles.

To explore the extension of Day Centre provision to cover weekends—particularly for Carers of people with Dementia.

Support for Carers to enter and remain in employment.

Clear criteria for the allocation of respite care/short breaks—especially in Childrens Services.

How will we get there?

Offer all Carers an assessment of their respite care/short breaks needs.

Develop clear guidelines, criteria and goals for children and adults using short breaks services.

Explore options to extend Day Care provision for Carers of people with dementia to cover weekends.

Ensure residential respite care/short breaks maintains clients mobility and abilities—listen to Carers about what should be achieved.

INTER-AGENCY WORKING - PRIMARY CARE SERVICES

The Scottish Executive sets out a clear message to General Practitioners and Primary Health Care Workers in its 2003 Health White Paper—Partnership for Care, and the Draft NHS Information for Carers document.

The clear emphasis is on the need to provide information about services to Carers at an early stage in caring and also to recognise Carers as key providers of care.

The isolation of many Carers means that their General Practitioner is their main point of contact for support and resources. The General Practitioner often only concentrates on the ‘patient’ but research by Carers National Association shows that a significant number of Carers suffer ill health through the prolonged effects of caring. As they are often the essential element in Health and Social Care it is important to ensure their well being.

Changes in the way Primary Health Care is delivered is perceived to have affected Carers’ ability to have their health needs recognised and dealt with in their own home. Most General Practitioners now rarely do regular home visits to older patients or those with disabilities, unless their condition is such that they are unable to make the journey to the Surgery. Although Carers have less opportunity to have a ‘quick word’ with the Primary Care Worker in their home there is still ready access to the community nurse who they can contact initially phone arranging a visit if it is required. However, if either they or their dependent have health worries they usually have to visit the surgery. The result is that they often put off making an appointment until things are really desperate or just don’t go at all.

In our written survey 80% of Carers did feel that their Doctors/Nurse/Social Workers did involve them when planning care for their relative/friend. However only 67% felt they were consulted about whether they could actually manage to care for their relative/friend.

“family input seemed of no interest to Doctors, Nurses and Social Workers.”

“I was not involved—doctors never consulted me.”

“if treatment is given by the GP, they are never interested enough to follow the patient up—the Carer is never consulted.”

In order to try and get information to Carers before a crisis occurs the Orkney Carers Centre wrote to all GP’s in Orkney to ask if they would be willing to identify Carers at an early stage in caring and give them the “Information for Carers” Booklet. The majority of GPs have agreed to take part in the initiative.

What do we need?

Carers need to look after their own health and have the information and support to be able to do so. Carers who have their health needs supported at an early stage have fewer repeat hospital admissions and emergency GP consultations and there are lower numbers of Carers who have problems with depression/back pain etc.

Carers may need information about the illness of the person they care for, and need to be involved in care arrangements. It is essential that permission is sought from the patient to share

information relating to their illness with their carer and primary care staff including GPs should routinely seek patients permission for this.

Carers should be recognised as ‘experts’ in their relative/friends health and wellbeing needs and deserve to be listened to if voicing health concerns.

Information about services should be readily available to Carers before they reach crisis point.

Carers need recognition as an essential part of Health and Social Care Provision.

A ‘lead person’ should be identified by NHS Orkney as a contact point for Carers Issues.

Carers may need – or wish to have - protective clothing such as gloves to carry out their caring role. NHSO will only provide gloves where the patient has a known infection; otherwise Carers have to provide these themselves. Help with this would be useful.

How will we get there?

Encourage Carers to identify themselves to Primary Care/Social Work/Hospital staff at an early stage in caring.

Involve all GPs and/or Primary Care/Social Work staff in giving Carers the “Information for Carers” booklet.

Ensure that Carers understand that those who are unable to attend the GP Surgery can be visited at home. During appointments – whether at home or in the Surgery – enquires should be made after the Carer’s health as well as the patient’s, preferably in private. Ensure that Carers know they can ring their community nurse for advice.

Listen and act on Carers concerns about their dependent’s health and give information about any illness they suffer from. Be aware of the difficulties of attending surgeries.

Within the limits of patients confidentiality keep the Carer informed as to medical condition needs and prognosis.

During routine health checks ask “trigger” questions to see if patient has a caring responsibility.

Develop Carer Awareness at staff training sessions for Primary Care Teams, Hospital staff and Social Work teams. Give staff information in a written form eg. with their pay slips, included with other written information etc.

Recognise how much stress some Carers are under and how it can adversely affect their health and quality of life.

Identify a ‘lead person’ for Carers Issues within the NHS and Local Authority.

Explore the provision of protective clothing or ways to reduce the cost of this for Carers.

HOSPITAL ADMISSION/DISCHARGE

Hospital Admission/Discharge is often a time when Carers feel totally excluded and helpless. Yet they are expected to look after the patient when they are discharged.

“I was not kept informed while my wife was in hospital..”

“No one even let me know when my husband was sent to Aberdeen—I just found out when I phoned but he was already on the way.”

Carers have valuable information that can assist hospital staff: the likes, dislikes and habits of patients. Yet on the ward there may be few opportunities for Carer and staff to share this information.

“The doctor would only see my mother on her own—she has dementia and he didn’t get the true story.”

Although Carers are permitted to act as escorts to relatives going to Aberdeen if they are very ill or disabled it is acknowledged that sometimes the criteria are rather restrictive. If the patient has a visual/hearing impairment travel and speaking to consultants can be difficult so their needs should be considered. Escort provision is at the discretion of the GP or Hospital Doctor.

Research has shown that hospital staff and doctors often wait until all test results are back before discussing issues with patients and Carers in order to have all the details – this can be perceived as with-holding information.

“My mother fell and was admitted to hospital. They did lots of tests but wouldn’t say why. After she came home I finally got hold of the GP to voice my concerns at her poor condition and was told she had terminal cancer.”

“Even when parent Carers have been in hospital with their child they do not always receive the information they need to care after discharge.”

Leaving information sharing until just before or after discharge leaves no time for involving Carers and discussing issues involved in caring. Often there is a delay before GPs or Community Nurses receive information after a patient is discharged.

What do we need?

To raise awareness amongst staff of the importance of the role and needs of Carers.

To include Carers in the assessment process on admission or at any stage during admission if the patient’s condition/needs change.

To involve Carers before discharge so that they are fully informed as to their relative/friend’s needs when they get home.

“I was told my husband could walk and care for himself—I discovered it took 2 nurses to walk him and someone to help him wash himself while in the ward.”

To ensure Carers are willing and able to care. A staggering 93% of those surveyed had never been asked if they needed any training to look after their relative/friend when he was discharged. Recognise that Carers as well as patients have spiritual as well as practical needs.

“Due to my husband’s dementia and physical problems I felt I couldn’t have him home—but I had quite a struggle to get staff to understand my problems—even though I was on crutches after a fall”.

Help for Carers who have difficulty in expressing or identifying their concerns at meetings set up to discuss their relative’s needs.

How do we get there?

Include training on Carers Issues for all hospital staff.

Induction of hospital doctors/GPs to include session on Carers.

Admission Policy to make explicit reference to when and how to identify and involve Carers, including encouraging staff to ask Carer’s advice about the patient, and making Carers aware of NHS Orkney’s Spiritual Care Policy and the Hospital Chaplaincy Service.

If patients are going south to hospital/appointment consider the need for a Carer to escort them if they have visual/hearing impairment, and the patient feels support is needed.

Clear communication at all times between Carer, patient and health professionals – however when the patient does not give permission to disclose any information this must be respected.

Ensure that there is ‘Carers input’ to both Admission Policy and Discharge Protocol.

Include in Discharge Protocol a section on ensuring Carers are willing and able to care for the patient—this includes being given appropriate information, assessment when appropriate and offered training, support or help with caring duties. Initial input may be needed from the Rapid Response Team to enable Carers to manage the first few days at home.

Make Carers aware of their right to an advocate to help them at discharge meetings.

PHARMACISTS

Pharmacists, with their premises in the centre of Kirkwall and Stromness, are some of the most accessible of Orkney's health care professionals for Carers living in or near the towns.

With the difficulties some Carers have in accessing medical care, there is real positive potential for minor ailments to be dealt with by the pharmacist. Sutherland's Chemist provides a very welcome service for Carers by delivering prescriptions—often it is very difficult to get out and collect medicines. Pharmacists also dispense drugs in dosette boxes to aid patients and Carers.

In the Carers Survey only 43% received advice/help from their local pharmacist—this however may be due to lack of knowledge of the services that can be offered.

For geographical reasons, all GP practices outwith Stromness and Kirkwall prescribe and dispense their own drugs so do not have pharmacists.

The Kirkwall and Stromness GPs operate a repeat prescriptions service whereby the prescription can be sent directly to the Chemist thereby reducing the need for the carer to go to the Surgery and collect it.

What we need?

Carers need early guidance on the effects and potential side effects of the drugs prescribed.

Carers may need guidance on how to use 'over the counter' medicine.

Carers may need help on how to work out how much of a medicine to give or may request pharmacists to dispense drugs in dosette boxes.

Carers need to be able to request and receive confidential advice—preferably in a private space rather than in the open shop.

Some method of identification to say they are a Carer and have permission from the person they care for to request information from the pharmacist may be useful.

How do we get there?

Information to Carers on what services are provided by pharmacists.

Carers encouraged to consult pharmacists about them/their dependent's health problems. They may need identification and their dependent's permission.

Investigate the possibility of a delivery service by both chemists for Kirkwall and Stromness.

Community pharmacists to raise awareness through outreach sessions eg. Day Centres, Lunch Clubs etc.

A private area available for consultation within the chemists.

PARENT CARERS

It is of great importance that parents of children with special needs feel that they are considered by professionals to be a full partner whose experience and views are sought and acted upon. Many feel that they are fighting to get services/equipment for their child and having to challenge the status quo.

The emotional side of caring needs to be recognised in this carer group, and support offered in the often daunting multidisciplinary meetings necessary to address the needs of the child.

70% of parents surveyed felt that they were part of the ‘team’ educating and caring for their child—however the figure reduced to 64% when asked if they received support and information when difficult discussions had to be made.

“I feel my worries are not taken seriously –if I request help there is no money.”

“Contact and information from school is sparse—I feel a bit out of it.”

“lip service is not enough—positive action is needed.”

The need for information at crucial stages is high on parents’ agenda. Delays in getting information/services/equipment can lead to important milestones in a child's life being missed.

Many parents feel there is little recognition given to the importance of treatment at an early stage—perhaps reducing the support needed later in life. It is recognised that investment at this stage can pay dividends by reducing further complications later in life.

What do we need?

To recognise parents’ knowledge and expertise and use these in developing partnerships between parents, teachers, health and Social Services.

Information, advocacy and support given to parents during the preschool, school and leaving school period.

Awareness of needs and entitlement in terms of practical and financial support (in form of benefit entitlement) of parents by education staff and other professionals.

Parents need to be aware of what type of respite care is available and the criteria for accessing it. They may also need to be made aware of how to access a Direct Payment if they wish to arrange their child’s care themselves.

Social development as well as the educational needs of the child should be addressed.

Forward planning strategies particularly in relation to the transition from children’s to adult services across all agencies.

“With children with special needs getting a baby sitter is a nightmare—early mornings or weekend help is impossible.”

How will we get there?

A ‘lead person’ or ‘champion’ for Carers of children with special needs.

A more accessible information booklet along the lines of “Information for Carers” booklet.

Open and clear criteria and information on respite services available in Orkney—particularly on the criteria used to access respite from Aurrida House, Family Focus, Home Start, Rachel House etc.

Establish protocols for planning transition from children’s to adult services.

Access to the Children’s Services Directory that was produced following consultation across the agencies by the Childcare Partnership.

MENTAL HEALTH/DEMENTIA

“I never know from day to day or even hour to hour how he will be.”

“His dementia has taken away the husband I knew – that in itself is a bereavement.”

Only 42% of those surveyed who cared for someone with dementia or a Mental Health problem felt they received the extra support they needed. Surprisingly it was not more time off which was most important to them but *“someone to confide in and support you”* followed by *“someone to come quickly in a crisis especially at night/weekends”*.

The majority of these Carers cared for someone with dementia and were full of praise for the Community Dementia Nurse, they felt he did not have time to support everyone however a recent increase in staff in this area will help in supporting this service and the patients and carers requiring it. There still remains the issue that there is no Psychogeriatric Consultant available to Orkney patients, and the specialist support and advice he/she would offer is a major gap in service.

A quarter of Carers surveyed admitted to suffering from stress or mental ill health themselves but fewer than half of these received any help for this.

“lack of sleep and his constant need for reassurance when he is awake is wearing me down—I feel so low at times and then feel guilty.....”

Many Carers have been and still are, isolated both by the stigma in our society towards mental illness and by professionals who perceive the family influence as a negative one. Carers often feel they have difficulty in getting General Practitioners/Community Psychiatric Nurses to accept that their relative is ill especially when they appear well when the General Practitioner/Community Psychiatric Nurse/other professional sees them. The erratic nature of severe and enduring mental illness means that patients and Carers needs fluctuate. The relationship between the Carer and the person they care for may be very fragile — and sometimes it is easier to deny their own needs to avoid confrontation.

Carers of relatives both with dementia and mental illness have a knowledge and understanding of the person that needs to be recognised by professionals. However they need information about the person they care for particularly about what their medication will do and any side effects to watch out for. Issues of confidentiality are sometimes perceived to be a reason to withhold information from Carers, but handled in a sensitive way enough details could be given to enable Carers to give care or to know when to request professional help.

The ‘Adults with Incapacity Act’ should be considered so Carers can be granted authority to make decisions regarding their relatives.

What do we need?

Recognition by professionals that Carers are an important part of the caring team and have particular knowledge of their relative.

A greater understanding by professionals of the isolation and distress experienced by Carers of relatives with a mental health problem.

Greater communication between professionals and Carers and relatives. It is however recognised that particularly where people have a mental health problem, professionals may not have permission to share information with relatives or Carers – the ‘Adults with Incapacity Act’ needs to be considered in some cases.

Recognition of the need for emotional as well as practical support. Acceptance that Carers needs fluctuate and appropriate respite care/support has to be available when it is needed.

A flexible respite/short break service which is acceptable to the Carer and their dependent recognising that people with dementia/mental illness do not always recognise the Carers need for a break.

How will we get there?

Offer a range of support services to Carers including the Orkney Carers Centre/Orkney Blide Trust, support groups, Advocacy etc. and ensure that they know how to access them. Ongoing commitment is needed by the Statutory Services to funding these Voluntary Organisations to ensure they are able to continue to provide support.

Give information about National Support Services eg. Alzheimer (Scotland) Action on Dementia, National Schizophrenia Fellowship, SANE line, Samaritans, Scottish Association for Mental Health—Depression Alliance etc.

Provide training for Carers on Mental Health/Dementia - informally done.

Develop the Hospital Discharge Protocol recognising Carers contribution and involving them in the process from admission onwards. The provision of information is essential here, but may prove difficult if mental health patient does not wish it to be shared with the Carer.

A flexible respite care/short breaks service. Day Care at Orkney Blide Trust, Social Services Day Centres or other provider or through Direct Payments. Increased day care should be explored to include weekend care for people with dementia. Crisis residential respite care preferably not in a hospital setting, and flexible home based respite care for Carers from Crossroads could also be options.

HOUSING

Everyone needs a decent place to stay at a price they can afford. Carers may have to move to be near to or live with the person they are caring for. The house may need to be adapted or new accommodation offered to enable the Carer to continue to care for their relative at home.

82% of Carers were satisfied with their relative or friends house but about half felt some adaptations would be helpful.

“housing adaptation did make life so much easier.”

“delighted with the house which was done with a Care and Repair Grant.”

However one Carer wrote *“We felt they ignored some crucial advice when ours was adapted and we have to live with the results.”*

What do we need?

Access to appropriate housing with access to transport, shops and community facilities.

Information on housing providers, who to contact for help with adaptations including bathrooms, steps, rails etc.

Priority housing for Carers to enable them to live near or with the person they care for.

How will we get there?

Housing providers to take account of and prioritise the housing needs of Carers, and include information on Housing Benefit, Council Tax Discounts etc.

Adaptations and equipment to be readily available to Carers particularly if there is a moving and handling issue.

Housing providers to raise the profile of Carers' housing needs when applying for Central Funding.

Ensure that Application Forms are easy to fill in and offer help when required.

Carers' Assessments focussed on housing need as part of the assessment process.

Carers' input valued, as often they are the experts on their relative/friends needs.

BENEFITS/INCOME MAXIMISATION

Raising awareness amongst Carers of financial benefits which may be available to them has always been a high priority in Orkney. Both Social Work Staff and Community Nurses encourage Carers and their dependents to apply for financial support and will assist them with filling in the sometimes daunting forms. This is reflected in the survey results where 80% felt they were managing financially and 77% knew which benefits were available.

However the Local Benefits Office maintains that the uptake in Carers Allowance is low in Orkney.

“I think I know what benefits are available but it is a bit of a maze.”

Carers were made aware of the benefits they were entitled to by a variety of sources, the main ones being Nurses (especially the Dementia Specialist Nurse) Social Workers, Crossroads and the Benefits Office themselves.

“We were quite surprised when the woman from the Benefits Office came to talk to the SNAP (Special needs children and young adults parents) Group. Few parent Carers were aware of their entitlements.”

Many Carers may have lost out in building up pension contributions—something that the Government is recognising and proposing to address.

What do we need?

Carers to be made aware, at an early stage of caring, about the range of financial help available.

Accessible information about Benefits available in a variety of formats.

Help with filling in forms and asking for a review when circumstances change.

Training for staff who are doing Single Shared Assessments to enable them to be confident in advising clients about Benefits they may be due.

How do we get there?

Insert a trigger question regarding Benefits in the Carers Assessment Forms.

Training for all staff involved in the assessment process about the benefits available and eligibility criteria.

Encouragement to Carers to apply for benefits, helping if required with the Application Form.

Information regarding benefits in the ‘Information for Carers’ booklet and a regular update on changes in the Carers Newsletter.

Referral of Carers to CAB (Citizens Advice Bureau) who have a Welfare Rights Officer.

CARERS IN EMPLOYMENT

“Stark choice between my caring role and paid worker requirements”.

“getting help in early mornings and school holidays makes trying to keep a job a nightmare.”

It is recognised nationally that 15% of employees also care for someone at home. Caring can be long or short term and the need to care can arise suddenly. Some employers in Orkney are very supportive of Carers, allowing them time off or flexible working in the short term. However if the caring role continues keeping a job becomes more difficult. A few Carers in Orkney have been treated very badly by their employers.

40% of Carers surveyed who do not have a job would like to work, even on a part time basis. To be able to do this they all felt they needed a sympathetic employer or someone to take over their caring role. However, 60% did not wish employment.

“As I am eighty and have osteoporosis I don’t think anyone would employ me.”

Many Carers are involved in Voluntary work—especially Parent Carers—this can be rewarding but can be another source of guilt and pressure when there are deadlines to be met.

What do we need?

Employers to recognise that some of their staff have a caring role and may have difficulty at times of crisis.

Appropriate alternative care or support for relatives during the hours the Carer is working.

How will we get there?

Raise awareness among employers about the caring responsibilities some of their staff may be undertaking.

Policies and Practices developed by employers to reflect these concerns.

Carers made aware of help available—particularly alternative care for the person they are caring for.

Service provision to give support to enable Carers to resume or maintain employment.

YOUNG CARERS STRATEGY 2005 – 2008

This strategy should be considered alongside the Orkney Integrated Children's Services Plan and Orkney Carers Strategy.

Introduction

Support for Carers was established as a priority with the introduction of the NHS and Community Care Act 1990. This Act provides the framework for implementing Community Care Policies and Procedures. The Carers (Recognition and Services) Act 1995 also acknowledges the crucial role of relatives and friends as Carers.

The Children (Scotland) Act 1995 reinforces the right of Carers to an assessment of their own needs, specifically in relation to parents and carers of children and young people affected by disabilities. It also states that children and young people, when affected by disability, are "children in need" and are therefore entitled to an assessment of their needs. At present therefore, Young Carers come within both adult and children's services.

The profile of Young Carers has been raised considerably by the UK Strategy "Caring about Carers" and the "Strategy for Carers in Scotland" both launched in 1999. NHS Carer Information Strategy requires NHS Boards to "specify the arrangements for involvement of Young Carers" and "develop strategic proposals to address the identification and information needs of specific carer groups such as Young Carers."

Throughout the document there are actual comments from Young Carers in Orkney.

The Purpose of the Strategy

The main aims of the strategy are:

- to place children and young people at the centre of agencies' thinking and planning
- to inform statutory and voluntary organisations of the need to create a greater awareness of who Young Carers are and the difficulties in identifying them
- to improve joint working and sharing of information and resources among agencies
- to consider how current legislation can enable agencies to provide good quality support to Young Carers
- to make services for Young Carers more available and accessible
- to identify areas of service that need to be developed

Definition of a Young Carer

"A Young Carer is a child or young person up to the age of 18, whose life is affected by caring, where the person being cared for has a disability, long term illness or mental health difficulties. Disability and long term illness are not restricted to physical disability or illness. They may also include, for example, mental ill health, learning disability, drug and alcohol use, HIV and AIDS (Glasgow City Young Carers Strategy)."

Young Carers may be divided into –

PRIMARY Young Carers - the sole carer of a disabled person

SECONDARY Young Carer - those who share caring with other family members.

This includes:

- children who are affected by another child's disability and are therefore not receiving the usual level of parental care or attention. They are therefore taking responsibility for caring for themselves beyond the level which would be expected of children of their age
- children who are providing care for an adult

Young Carers mostly care for parents or siblings, but they may also care for grandparents, other family members or friends.

Caring tasks may vary, obviously depending on the condition of the person they care for and their own age and ability. The tasks may include:

- domestic chores
- help with moving around
- giving medication
- offering emotional support
- providing intimate personal care
- looking after brothers and sisters
- paying bills and looking after money in the home

“I look after my sister so that Mum can make the tea – sometimes I would rather play with friends instead.”

Young Carers, within the definition used in this strategy may include children who are quite young. For example, a 5 year old who gets his own breakfast before going to school because his parent is busy caring for a disabled sibling, is caring for himself beyond what may be usual. A 6 or 7 year old who regularly checks a sibling is safe and well because a parent is disabled, is helping with their care beyond what is usual for a child of that age.

Identifying Young Carers in Orkney

Difficulties in identifying Young Carers are a national as well as a local problem. This was highlighted locally in 2000 while the Orkney Carers Centre carried out a multidisciplinary audit to try to discover the number of Young Carers in Orkney.

The Young Carers themselves are often reluctant to identify themselves. Some may be frightened and embarrassed about the illness or disability of the person they care for. Others may be worried that the family will be split up if the authorities discover their situation. Many do not realise that help may be available to enable them to continue caring with support.

“Now that I’m 16, I feel better about saying that I’m a young carer as no-one can say I shouldn’t be doing what I’m doing.”

Some professionals working with families with disability and other problems are not recognising the caring input by children and young adults. They are also failing to recognise the impact family disability, illness, mental health problems or alcohol misuse is having on the child or young person's life.

“I get ignored all the time and told I have to help out. Most of the time I don’t mind but sometimes I want to shout ‘I’m only 10!’ and then I feel bad for even thinking it because I know I’m very lucky really.”

In schools, staff rely on the young person identifying their situation, and not all Young Carers want to do this. National figures also show that approximately 10% of Young Carers have one or more parents who is alcohol dependent and up to 20% have parent/s affected by mental illness.

One purpose of the strategy must be to highlight concerns about the 'visibility' of Young Carers and to raise awareness of it as an issue. Research into Young Carers has demonstrated both physical and psychological ill effects from caring, which may only become apparent in later life. However it should be recognised that many Young Carers find caring a positive experience – especially if adequate help is available.

“Although Mum is in a wheelchair, and I have to help her in the house, I like it because she is always there for me and not out working like my friends’ Mums.”

In a survey into bullying the Princess Royal Trust for Carers carried out in 1999 ("Too much to take on") 80% of Primary Young Carers and 71% of Secondary Young Carers were bullied at school. This is recognised in the schools’ “Anti-bullying” Policy as it states that caring children can be the subjects of bullying.

"Children in families where a parent suffers from mental illness can be at risk of developing mental health problems. Around 10,000 children across the country are in this position. Department of Health work shows that 30% of mentally ill adults have dependent children. Between a third and two-thirds of children who have a mentally ill parent will develop problems themselves. In families where alcohol or drug abuse is a problem, children can be faced with a caring role which can create great anxiety or worse".

Frequent effects for children and young people of providing care

- problems at school, with completing homework and in getting qualifications;
- isolation from other children of the same age and from other family members;
- lack of time and finance for play, sport or leisure activities;
- conflict between the needs of the person they are helping and their own needs, leading to feelings of guilt and resentment;
- feeling that there is nobody there for them, that professionals do not listen to them and are working only with the adult;
- lack of recognition, praise, or respect for their contribution;
- feeling that they are different from other children and unable to be part of a group;
- feeling that no one else understands their experience;
- problems moving into adulthood, especially with finding work, their own home, and establishing relationships.

(from Social Services Inspectorate England and Wales Report November 1995)

“They kept shouting at me for not doing my homework but no-one ever asked me why I couldn’t do it.”

Young Carers' Rights

It is difficult to frame a set of guidelines or recommendations that rest comfortably between the contradictions and tensions inherent in being a child and a Carer. A starting point, however, is to identify a set of rights that can form the bedrock from which more detailed and specific guidelines, recommendations or approaches can be developed. These rights are tantamount to a statement of principle. We believe that Young Carers, as children and as carers, have:

- the right to self-determination and choice (to be children, carers or both);
- the right to be recognised and treated separately from the care receiver;
- the right to be heard, listened to and believed;
- the right to privacy and respect;
- the right to play, recreation and leisure;
- the right to education;
- the right to health and social services specific to their needs;
- the right to practical help and support, including respite care;
- the right to protection from physical and psychological harm, (including the right to protection from injury caused by lifting etc);
- the right to be consulted and be fully involved in discussions about decisions which affect their lives and the lives of their families;
- the right to information and advice on matters that concern them and their families (including benefits and services, medical information etc);
- the right to access to trained individuals and agencies who can deliver information and advice with appropriate expertise, in confidence;
- the right to independent and confidential representation and advocacy, including befriending or 'buddying';
- the right to a full assessment of their needs, strengths and weaknesses, including full recognition or racial, cultural and religious needs;
- the right to appeal and complaints procedures that work;
- the right to stop caring

(From Aldridge J and Becker S (1993) Children who care: inside the world of Young Carers)

Young Carers Needs

Young Carers have individual needs that are specific to their situation, but many Young Carers have very similar needs to each other. The following list of needs has been gathered from our experience in Orkney.

- To be recognised as a Young Carer and given support to continue in this role if so wished.
- To have access to support from professionals in health care, social work, education and the voluntary sector.
- To have understanding and support from school when caring affects the Young Carers ability to concentrate in class or do homework.

- To be involved in an activity out with the home, allowing the young carer to let off steam.
- To be a member of a group of Young Carers, who understand the issues they are facing daily and to whom they do not have to explain themselves.

Services available in Orkney for Young Carers

Young Carer Support Groups – run by a Young Carers Support Worker who is employed by the Orkney Carers Centre.

Individual Support – for Young Carers by Young Carers Support Worker.

Orkney Carers Centre - advice, information and support for all Carers.

Crossroads (Orkney) - respite care for all Carers often specifically arranged to assist Young Carers.

Family Focus and Aurrida House - respite care for disabled children allowing their family a break.

Community Care Services for disabled parents, to ensure Young Carers are not overburdened.

Children & Families Services for children with special needs, thereby giving the parents time with other siblings.

Summer Playscheme – for children with special needs.

Guidance Staff, School Nurses, Social Work - support in KGS and Stromness Academy.

School Nurse/Social Work – support in all Primary/Secondary schools.

The way forward in Orkney-recommendations

- Professionals who may be in contact with Young Carers who are dealing with disability in the family or are affected by mental health problems and drug and alcohol misuse should receive training in recognising them as Young Carers and assessing any needs they may have.
- The Carers Centre should continue joint work with Education Services to raise awareness of Young Carers in schools and to provide training about the needs of Young Carers and how to support them within schools.
- The subject of 'Young Carers' should be part of the Personal and Social Development curriculum. Relevant materials e.g. Young Carers booklets could be made available to all primary and secondary schools in Orkney.
- Young Carers Support Groups should be further developed to include young people in families where

there is alcohol/drug dependency or mental health issues.

- The Young Carers Strategy will be an integral part of the Orkney Carers Strategy and the Integrated Children's Services Plan.
- The Young Carers Strategy will be reviewed along with the Orkney Carers Strategy in 2007.
- Specific work with Young Carers to assess the levels of bullying in Orkney.
- Development of an interactive CD-ROM, with a paper version, to facilitate Young Carers Assessments.

ORKNEY CARERS STRATEGY 2005-2008

ACTION PLAN 2005-2006

HEADING	ACTION POINT	ORGANISATION RESPONSIBLE	DATE OF COMPLETION
INFORMATION	<p>Update 'Information for Carers' booklet annually. Distribute to GP Practices, NHS Orkney venues, Community Social Services Department, Voluntary Sector and public information areas.</p> <p>Provide a 'Carers Identification Card' with service user / patient permission slip</p> <p>Include 'Carers Awareness' in staff training/induction of NHS Orkney Staff, Orkney Islands Council Staff and Community Social Services Department staff.</p> <p>Amend Discharge Protocol to ensure training and support needs of carers are identified and addressed.</p> <p>Develop training for Carers as part of preparing them to care and as an on-going resource.</p>	<p>Orkney Carers Centre</p> <p>Orkney Carers Centre</p> <p>Orkney Carers Centre Designated staff in Statutory Services</p> <p>NHS Orkney / Community Social Services Dept</p> <p>Orkney Carers Centre NHS Orkney</p>	<p>February each year</p> <p>October 2006</p> <p>April 2006</p> <p>April 2006</p> <p>April 2006</p>
COMMUNITY SOCIAL SERVICES DEPARTMENT	<p>Ensure that Carers are included in the assessment of the person they care for and that their caring input is included in the care plan and their ability and willingness to continue caring is considered.</p> <p>Ensure regular updating of user-friendly publicity about services available.</p> <p>Identify a Lead Person as a contact point for Carers.</p>	<p>Community Social Services</p> <p>Community Social Services</p> <p>Community Social Services</p>	<p>On-going</p> <p>April 2006</p> <p>October 2005</p>

ASSESSMENT	<p>Carers Assessments must be offered to all Carers, and if they wish an assessment, a choice given as to whom they would like to help them complete it.</p> <p>Ensure Carers training and support needs are identified in Assessment</p> <p>Monitor the numbers of Assessments completed.</p> <p>Record Unmet Needs.</p>	<p>Orkney Carers Centre Community Social Services NHS Orkney</p> <p>Community Social Services NHS Orkney</p> <p>Orkney Carers Centre Community Social Services NHS Orkney</p>	<p>On-going</p> <p>On-going</p> <p>On-going</p>
SHORT BREAK/ RESPITE CARE	<p>Guidelines on availability and allocation of resources; criteria for access to respite and short breaks; and goals for service users to be developed by all Respite & Short breaks services (Children & Adults).</p> <p>Explore how to finance extended provision in Older People's Day Services to include weekend day care for people with dementia.</p>	<p>Community Social Services</p> <p>Community Social Services</p>	<p>2006</p> <p>November 2006</p>
PRIMARY CARE SERVICES	<p>Identify a Lead Person as a contact point for Carers.</p> <p>Identify Carers at an early stage of caring and ensure that they have information as to support available for them.</p> <p>Issue all GP Practices, Hospital Wards, Community Social Services Staff and Public Areas – with 'Information for Carers' booklet</p> <p>Encourage Primary Care Staff to support Carers to look after their own health as well as the person they look after.</p> <p>Explore arrangements to fund and provide protective clothing.</p>	<p>NHS Orkney</p> <p>General Practitioners NHS Orkney</p> <p>Orkney Carers Centre</p> <p>General Practitioners NHS Orkney</p> <p>CSS</p>	<p>October 2005</p> <p>On-going</p> <p>On-going</p> <p>November 2006</p>

HOSPITAL ADMISSION/ DISCHARGE	Training on 'Carers Awareness' amongst hospital staff.	NHS Orkney	April 2006
	Admission Policy to make explicit reference to when and how to identify and involve Carers at all stages.	NHS Orkney	December 2005
	Discharge Protocol to include ensuring Carers are willing and able to care for their family member/friend.	NHS Orkney	April 2006
	Make sure all Carers are aware of their right to have an Advocate to help them at a discharge meeting.	NHS Orkney	October 2005
	Fund Carers as escorts for patients with sensory impairment who need this.	NHS Orkney	April 2006
PHARMACISTS	Include information on local Pharmacists in the 'Information for Carer' booklet.	Orkney Carers Centre	September 2005
	Explore whether possible to provide a private area in local pharmacies for Carers to consult Pharmacist.	Boots and Sutherlands	September 2006
	Provide outreach sessions by local pharmacies.	Boots and Sutherlands	On-going
	Encourage Carers to consult Pharmacists about minor health problems.	All staff	On-going
	Provide Carers Identification Card – include permission slip with this.	See information section	

PARENT CARERS	<p>Publish an information booklet for parents of children with special needs. Ensure access to the Children's Services Directory.</p>	<p>Orkney Carers Centre Integrated Community Schools Childcare Partnership</p>	<p>April 2006</p>
	<p>Develop protocols for planning transition from childrens' to adults' services.</p>	<p>Community Social Services NHS Orkney Education Department</p>	<p>January 2006</p>
	<p>Identify a 'Lead Person' or 'Champion' for Carers of children with special needs.</p>	<p>NHS Orkney</p>	<p>October 2005</p>
	<p>Publish open and clear criteria and information on Respite Services available in Orkney. (see section on Respite / Short Breaks).</p>	<p>Community Social Services</p>	<p>November 2006</p>
MENTAL HEALTH/ DEMENTIA	<p>Continue to provide services for both service users with mental health problems and dementia within the Voluntary Sector.</p>	<p>Voluntary Sector Providers and Statutory Services</p>	<p>On-going</p>
	<p>Investigate the need for short breaks/respite care for Carers of people with Mental Health Problems.</p>	<p>Orkney Carers Centre Orkney Blide Trust Community Social Services NHS Orkney</p>	<p>April 2006</p>
	<p>Provide more national support information, and local, informal training. See also Hospital Admission / Discharge.</p>	<p>Crossroads (Orkney)</p>	<p>Ongoing</p>
HOUSING	<p>Deal sympathetically with Carers housing needs – especially if they need to move to live with or to be near the person they care for.</p>	<p>Housing Providers</p>	<p>On-going</p>
	<p>Prioritise adaptations to houses – especially if there is a moving and handling issue. Carers' views should be listened to when planning adaptations.</p>	<p>Care and Repair Housing Providers</p>	<p>On-going</p>
	<p>Address Housing needs in all Assessments.</p>	<p>Crossroads (Orkney) and all Assessing Agencies</p>	<p>On-going</p>

BENEFITS/INCOME MAXIMISATION	<p>Provide training for all Assessment and Care Management Staff on the Benefits available to Carers and their eligibility criteria.</p> <p>Insert a trigger question on Benefits in the Carers Assessment Forms.</p> <p>Provide up to date Information on Benefits in the 'Information for Carers' booklet.</p> <p>Ensure that Carers receive help in filling in Benefits Forms if required.</p>	<p>Local Benefits Office Community Social Services</p> <p>Orkney Carers Centre</p> <p>Orkney Carers Centre</p> <p>Citizens Advice Bureau Orkney Carers Centre</p>	<p>On-going</p> <p>January 2006</p> <p>On-going</p> <p>On-going</p>
CARERS IN EMPLOYMENT	<p>Raise awareness among employers about the caring responsibilities of some staff and encourage them to have a 'Family Friendly Policy.'</p> <p>Carers Assessments to include attention to employment needs and potential.</p>	<p>Orkney Carers Centre</p> <p>Crossroads (Orkney) and all Assessing Agencies</p>	<p>April 2006</p> <p>Ongoing</p>
YOUNG CARERS	<p>Young Carers Support Groups should be further developed to include young people in families where there is alcohol/drug misuse or mental health issues.</p> <p>Develop an interactive CD-ROM, with a paper version, to facilitate Young Carers Assessments.</p> <p>Specific work with Young Carers to assess levels of bullying in Orkney.</p> <p>Work to raise awareness in Education Services and include attention to Caring Roles as part of Personal and Social Development.</p>	<p>Orkney Carers Centre NHS Orkney Community Social Services</p> <p>Information Plus Orkney Carers Centre NHS Orkney Community Social Services</p> <p>Orkney Carers Centre Education Department</p> <p>Orkney Carers Centre Education Department</p>	<p>April 2006</p> <p>November 2006</p> <p>April 2006</p> <p>Ongoing</p>