



ABERDEENSHIRE CARERS STRATEGY

2006 – 2009

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EXECUTIVE SUMMARY

Caring is becoming a significant factor in the lives of many Aberdeenshire citizens. This Strategy aims to set out how Carers can be supported in their caring role and the actions that are planned to achieve these aims.

This Strategy recognises the significant role of Scotland's National Strategy for Carers which was published in 1999. The Aberdeenshire Carers Strategy 2006 – 2009 builds on previous strategy documents and represents the local plan for our area. The document is divided into 10 sections and is accompanied by an Action Plan for 2006 setting out how the recommendations will be transferred to practice.

Aberdeenshire Council and NHS Grampian recognise that Carers need specific supports to carry out their role. Both agencies are committed to seeing Carers as key partners in the provision of care.

Section 1 sets the context of the Strategy document and acknowledges that although statistics vary there could well be around 27,000 adult carers in Aberdeenshire at any one time and around 6,400 young carers. Carers undertake a broad range of tasks for the people they care for including, personal care, medical, financial, practical, emotional and social supports. The caring role can be a full-time job or, as is often the case, juggled with a number of other commitments for example to family or employment. This Strategy endorses the Aberdeenshire Carers Charter and re-emphasises the Charter's principles which inform how we will work with Carers.

Section 2 examines the Legislative Framework and sets out Carers rights under that framework. Specific detail is given of the 2002 Community Care and Health Act with reference to other relevant legislation detailed in Appendix 2. This section also acknowledges the report and recommendations arising from the research, The Future of Unpaid Care in Scotland.

Section 3 deals with Assessment and discusses current practice within the context of the targets for improvement. Eligibility to assessment is outlined and the central role of assessment in effectively supporting Carers is discussed.

Section 4 focuses on the Information needs of Carers and looks at the types of information required and the various sources of that information. The Strategy challenges situations where information has been withheld from Carers which they need in order to undertake their role as Carer.

Section 5 examines provision and practice in terms of Respite/Short breaks. The benefits of breaks from caring are discussed and information is provided about the different ways that respite is financed. The different meaning of respite for adult carers and young carers is noted and there is a call for

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improved equity of short breaks provision both across the different areas of Aberdeenshire and across different carer groups.

Section 6 recognises the vital role of Carer Involvement in planning and developing services. However, the section highlights the practical difficulties of ensuring such involvement takes place and suggests actions to improve the record on carer involvement in Aberdeenshire.

Section 7 covers Carer Support. It is acknowledged that the majority of carers support services are provided through the Voluntary sector. The particular challenges of supporting carers in rural areas are noted. The section outlines the range and type of services that are available now and aimed for in the future.

Section 8 focuses in specific on the needs of Young Carers. Although many other parts of this document are relevant to young carers the very different needs of this group are recognised here. The different reasons for young carers taking on caring roles are noted alongside the impact of caring on young people. There is a recognition that at all levels more needs to be done to meet the needs of this group.

Section 9 looks at Carers Health and Well-Being. Caring is recognised as a public health issue – a fact that has now been noted in both research and statutory reports. The impact of caring on physical and emotional health is examined, with particular emphasis on the emotional distress caring can cause. The recommendations of the Kerr Report are highlighted and noted. The issue of stigma is looked at in detail.

Section 10 outlines the specific financial framework which is used to take forward some aspects of the Strategy, namely the Carers Strategy Budget.

FOREWORD

Welcome to the Aberdeenshire Carers Strategy 2006 - 2009. In this document we will set out both our vision for carers support and services over the next 3 years and the action we will take to achieve that vision.

The **aim** of this strategy is to improve the life of carers living in Aberdeenshire. The information will be relevant to a wide group of people with an expected 3 in 5 of us taking on a caring role at some point in our lifetime.

This strategy is for **all** carers. However, it is acknowledged that carers are **not a single group** of people. As a result you will find the needs of carers being addressed in a number of other strategies and plans dealing with specific issues. For example, *Challenging Disability Strategy, Brain Injury Strategy, Strategy for Mental Health and Well Being, Integrated Children's Service Plan*

This document will provide an **overall framework** for the work we will do with and for carers.

Addressing the needs of carers has become a key issue for both Aberdeenshire Council and NHS Grampian. This is partly due to the requirements of legislation but also due to the increasing recognition of the role carers have.

We are **committed** to providing responsive and appropriate services which support carers in their caring role. Through this strategy and the accompanying action plan we aim to show how this will be achieved.

SECTION 1 – INTRODUCTION

Who are Carers?

Carers look after family, partners, friends or neighbours in need of help because they are ill, frail, have a disability or substance misuse problem. The care they provide is **unpaid**.

Caring can involve assistance with any or all of the following:

- Personal care – washing, dressing or feeding
- Assistance with medication and/or other medical care
- Collecting benefits, pensions and dealing with finances
- Emotional and/or social support
- Acting as an advocate or guardian
- Practical assistance with daily activities – preparing meals, shopping, housework
- Physical assistance – support to mobilise or transfer

Some carers provide care for a few hours a week whilst others are providing care round-the-clock. Some carers give up work to care. Others juggle caring with work. In Aberdeenshire almost 60% of carers are in employment (2001 Census).

It is known that many people do not recognise themselves as carers. It is also known that most people want to care. However, caring can cause stress and have an impact financially, practically, physically and emotionally. Statutory services

therefore need to be proactive in enabling carers to feel more supported.

How many Carers are there?

Establishing accurate data for the number of carers in Aberdeenshire is very difficult. This is because the available statistics paint different pictures, definitions vary and because for every carer known to statutory services there are likely to be a number of carers who are not known. The number of these 'hidden carers' can only ever be guessed at.

The 2001 Census found that there were 481,579 carers in Scotland. Of these 11,269 were young carers under the age of 16. The breakdown of these figures for Aberdeenshire was 17,009 carers with 422 of these being young carers.

Although the Census data has to be treated currently as the most reliable source of information it is worth noting that other studies and research have indicated that there are many more carers in Scotland than the 2001 Census suggests.

For example, the Scottish Household survey 2002 – 2003, which uses sampling techniques, estimated that there were 165,100 people in Scotland providing care to someone within their own home and 503,400 people providing care outwith their own home. This represents approximately 13% of the total population. Of those

providing care within their own home 4,900 were identified as young carers under the age of 16. This represented 0.5% of the total population of under 16s in Scotland.

Recent research by OPM¹ found that 12% of the adults surveyed perceived themselves to be carers. This would equate to over 600,000 of the total Scottish population and give an indicative figure for Aberdeenshire of over 27,000.

Similarly a study² of young carers in Perth and Kinross found 13.5% of school respondents were identified as young carers. If this were translated to Aberdeenshire we would be estimating the number of young carers to be around 6,400.

Consequently, we can only make a guess at how many carers there actually are in Aberdeenshire. But we are clear that:

- caring is becoming a **significant factor** in the lives of many people in Aberdeenshire
- the number of people taking on a caring role is likely to **increase** in the future, and
- that all carers should be offered **support** in undertaking their caring role.

Why is a Carers' Strategy needed?

A Strategy is usually produced to set out the general strategic direction a Government or Local Authority wishes to take. The strategy and accompanying action plan should detail the outcomes we want to achieve, how we intend to achieve them, the timescales in which the work will be done and the resources which are available.

In February 1999 the UK Government published "Caring about Carers" a National Strategy for Carers. Later in November of that year the Scottish Parliament produced a 'Strategy for Carers in Scotland'. This mirrored the UK document but focussed specifically on delivery in a Scottish context. Local Carers Strategies followed on from the national plan reflecting developments and service planning for each area.

This Strategy builds on the previous Aberdeenshire Carers Strategy. It has been developed to support carers. The Strategy aims to provide a framework to ensure that services and support are in place and, by working in partnership with carers, to improve current services and identify priorities and objectives for developing services in the future.

The development of this strategy document has been undertaken by a series of working groups involving carers, staff from Social Work, Health and Voluntary sector agencies. A note of the membership of the working groups can be found in Appendix 1.

¹ Office for Public Management/Scottish Executive (April 2005) Draft report – Future of Scottish Unpaid Carers: National Household Survey – Main findings.

² Reported by Prof.S.Becker – Conference presentation – 6th June 2005 – Supporting Young Carers – A future through partnership, PRTC, Edinburgh

What is the Carers' Charter?

The Aberdeenshire Carers' Charter has been in place since 1998. The Charter states how Aberdeenshire Council and NHS Grampian aim to meet the needs of carers by listening to carers, providing flexible and well co-ordinated services and by promoting and developing good practice. The principles of the Charter are outlined below. **These principles are the basis for all our work.**

- 1. Choice** Enable carers to choose whether or not they wish to take on or continue with a caring role
- 2. Respect for the individual** Respect each individual carer as a partner in caring who has expertise and skills and as a person who may have needs for services in their own right
- 3. Equal opportunities** Provide equitable services throughout Aberdeenshire. Provide an effective complaints procedure. Not act selectively towards carers out of prejudice
- 4. Safeguarding rights** Provide a confidential service and provide access to advocacy services and information and advice about services and carers' rights
- 5. Consumer voice** Seek and listen to the views of carers and enable them to take greater control
- 6. Quality** Offer services that are of a high standard not only to those that they care for but also for themselves. Aim to improve service continuously
- 7. Equity** Allocate resources fairly
- 8. Service delivery** Deliver services to carers in their own community

SECTION 2 – LEGISLATIVE FRAMEWORK

What does the legislation say?

There are a number of Acts that are or could be relevant to carers. In this section we will concentrate on the Community Care and Health (Scotland) Act 2002. A fuller list of relevant legislation can be found in Appendix 2.

The **Community Care and Health (Scotland) Act 2002** significantly reinforced and expanded the rights of carers to an **independent assessment** and strengthened the role of carers in the assessment process.

The fundamental principle underlying the provisions of the Act is that Local Authorities, the NHS and other support agencies should recognise and treat carers as **key partners in providing care**. In doing so staff need to recognise and draw on the knowledge and expertise carers have about the person they care for.

The Act also:

- Places a duty on Local Authority and Health staff to **inform** carers of their right to an assessment where it appears that the person is a carer.
- States that carers have the **right to request** an independent assessment irrespective of whether the authority is assessing the needs of the cared-for person. This right to request an independent

assessment **includes young carers** under the age of 16 and **parent carers** who are caring for children with a disability.

- States that when the Local Authority is undertaking an assessment of a cared-for person they **must** take into account the needs of the carer.
- Instructs Health services to develop an **information strategy** for carers advising them of their rights as a carer.

You will find more information about assessment in the next section of this document.

The Act does not provide for services to carers but focuses on the carers' need for resources to carry out their caring role. Resources may be in the form of care services to help support the cared-for person, or support and advice provided directly to the carer.

Whilst the 2002 Act concentrates on carers' assessment it is noted that the Scottish Executive's policy on supporting carers addresses wider issues about achieving good outcomes for carers.

Good outcomes include:

- A carer being able to cope better with their caring role
- A carer getting a regular break from caring
- A carer being better informed

- A carer feeling valued, supported and listened to.

In Aberdeenshire we will strive to achieve the same good outcomes.

The Future of Unpaid Care in Scotland

Between October 2004 and August 2005, the Care 21 Unit within the Scottish Executive, together with the Office for Public Management (OPM) a leading public sector research and consultancy organisation, undertook a project looking at the future needs of unpaid carers and how services might need to change over the next 10 years. The project involved working with carers, carers support and statutory organisations engaged in the delivery of services for both service users and carers. The Headline report includes 22 recommendations. It is anticipated that the recommendations within the report will consolidate existing thinking on support for unpaid carers, whilst also creating new solutions for the future. The Report and recommendations, and the Appendices can be accessed through the Scottish Executive website www.scotland.gov.uk

SECTION 3 – ASSESSMENT OF CARERS NEEDS

Introduction

As detailed in the previous section carers have a right to an assessment. However, in practice we have found that many carers are unaware of this right and are unaware whether an assessment has or has not been carried out. Equally carers have told us that staff working with them are not informing them of their right to an assessment, not undertaking assessments and even when assessments have been carried out not making this explicit to the carer.

We also expect that when assessments of cared-for persons are being undertaken the assessment takes account of the experience, expertise and knowledge of the carer and that any subsequent service provision takes account of the views and needs of the carer. Carers have told us that this does not always happen.

Aberdeenshire Carers Strategy is clear that this situation **needs to change**.

The need for change

In the Introduction section of this document reference was made to the number of carers in Aberdeenshire and the nature of the caring role. This Strategy acknowledges that carers play a vital role in the provision of both health and community care. Carers' support in Aberdeenshire is worth an estimated **£200 million a year**.

Carers really are key partners in care and have to be seen as such.

We also acknowledge that caring can have an adverse affect on health, well being, education, employment, finances, social life and can lead to practical and emotional difficulties. It therefore clearly makes sense to ensure that as many people as possible are enabled to continue caring by recognising their invaluable contribution and by developing services which support them. Carers' assessment has a central role in achieving this.

Who is eligible for an assessment?

The Community Care and Health (Scotland) Act 2002 defines carers who provide or intend to provide “**a substantial amount of care on a regular basis**” as being entitled to an assessment. In other words carers whose caring role is likely to have an impact on their health, lifestyle, education or employment status and who may need support to continue caring, should be assessed.

If you **are** or **intend** to provide a substantial amount of care on a regular basis for another person you have the right to request an assessment even if the person you care for has not been assessed, is refusing an assessment or is still in hospital. The assessment will be of what in law is termed a carers'

“ability to care and continue to care”.

If you care for a person who is 18 or over and who would be eligible for community care services, then you are entitled to an assessment. Community care services are for people who are older, ill or frail, people with disabilities, people with mental health problems, people with substance misuse problems, people requiring palliative care and people with HIV, AIDS or Hepatitis.

If you care for a person under 18 who is eligible for children’s services you are entitled to an assessment. This means a child who is disabled, has special needs or has mental health problems.

If you are a young person under the age of 18 whose development is being placed potentially at risk by your caring role or your environment, and/or you are a child affected by disability then you are entitled to an assessment.

The present situation

At the moment the main mechanism for assessing carers support needs is through consideration of their needs as part of the assessment for the cared-for person. This provides an integrated family-based approach which does not see either the service user or carer in isolation.

Whilst in many situations this approach is entirely acceptable and appropriate it has become increasingly evident that this practice risks failing our duties under the legislation and more importantly failing the needs of carers. The practice also doesn’t take account of situations where a

cared-for person is not being assessed and it is unclear how practice is monitored.

Although individual carers assessments are now part of practice and are in some cases being carried out, they are not being carried out in sufficient numbers. Consequently, the record on carers’ assessment in Aberdeenshire is poor.

For young carers most assessment is currently carried out informally by young carers support workers (see page 24). Again there has been an increasing recognition that this situation is inadequate.

A lot of work has been undertaken recently to move carers assessment forward and to improve the service we provide to carers. Most gains have been made in adult services where new procedure and guidance are in the beginning stages of implementation. We anticipate that this will make a significant difference to carers.

SECTION 4 – INFORMATION

Introduction

Research studies have continually identified the provision of accurate, appropriate and accessible information as a **priority need** for carers. Some of our own discussions with carers have highlighted this point. For example, at a recent event with carers in Peterhead³ the following points were made:

“I need more information made available about the rights of carers”

“I would like to see more information for carers”

“I would like to see a local list of things to help carers. Have information on hand”

A similar picture is found across Aberdeenshire and indeed across Scotland⁴, with carers often saying that they only found out about **by chance** the supports and services that could assist them.

Information is important to carers so that they can carry out their caring role. Information about carers is also important to statutory services so that we can plan and deliver better services.

What information is required?

Carers are a diverse group of individuals who require a wide

range of information that is accessible, relevant, understandable and offered at the right time.

Of equal importance is how the information is targeted and delivered in a rural location like Aberdeenshire.

Amongst other types of information carers need information about entitlements to benefits and concessionary schemes both for themselves and the person they care for. Carers also need information about accessing breaks, support organisations, practical supports and services.

There is a need to improve information on health care, including good information on first contact, information on the health needs, treatment and support of the cared-for person. As well as information and involvement in admission and discharge planning. NHS Grampian Draft Carers Information Strategy 2007-2010 is currently out for consultation. The strategy will help to identify people who are unpaid carers, and to ensure that they have the information and support they need.

As stated earlier it is important to recognise and respect carers as partners in the provision of care. Therefore carers require

³ Spring into Summer: Carers Event, NE Aberdeenshire Carers Centre, April 2005

⁴ Office for Public Management/Scottish Executive (April 2005) Draft report – The Future Needs of Unpaid Carers – Final report

information about the cared-for person. This is critical to choice and control for the carer when deciding the level and nature of their caring role. Information is also vital for the protection of the health and well being of the carer and cared-for person.

from carers when they need it in order to carry out their caring role.

The present situation

Within Aberdeenshire information is provided to carers from a **wide range of sources**. Staff in the voluntary sector, Social Work and Health are all involved in information provision and there is a wide range of literature and leaflets available. Grampian Care Data is a key source of information provision and carers have access to both web and telephone information.

However, one of the most common difficulties identified by carers is **knowing where to go** to get the information they need. This is especially the case for new carers. Although it seems an obvious thing to say, you only find out you didn't know something when you find out about it. This often means that information doesn't reach carers at the right time.

Problems are still occurring in cascading information material to staff, users, carers and the wider community. We need to try to resolve this.

In addition, some carers have told us that information is not shared with them because practitioners say they are bound by confidentiality. Whilst this Strategy accepts that confidentiality is a sensitive area, which quite rightly needs to be respected, we do not accept information being withheld

SECTION 5 – RESPITE/SHORT BREAKS

Introduction

Respite Care/Short Breaks is a collective name given to the range of services that offer short periods of care to children and adults with care needs, and at the same time provide a break for their carer from caring responsibilities.

Respite means different things to different people. There are particularly wide differences in what respite means to adult carers and what respite means to young carers.

For adult carers most respite provision involves services being provided for the cared-for person so that the carer can take a break. For example, a short stay for the person being cared for in a care home; day centre provision or sitter and outing services for the cared for person. Respite therefore can range in duration from a couple of hours to a number of weeks. It can be arranged on a planned basis or in response to emergencies.

For young carers respite provision is about being provided with the opportunity to have some fun away from their caring situation and to have opportunities for leisure time with other young carers. Young carers need access to both individual and group activities.

The value of respite/short breaks

Adult carers place respite care as their **top priority** for service development and respite services are often highly valued. Young carers value respite because it

helps to address some of the difficulties they face. For example, Carers UK⁵ found that young carers had limited opportunities for social and leisure activities, a lack of understanding from peers, restricted friendships and experienced feelings of exclusion.

Respite is an important part of being able to cope as a carer. A break from caring is invaluable in reducing the psychological and emotional stress faced by many carers. Access to support services and breaks can also help carers to continue providing support⁶.

Paying for respite/short breaks

Some respite/short break services are charged for and the person using the service will be financially assessed to determine the contribution they will make towards the overall cost. Other services, in particular certain types of carer support, are not charged for and Aberdeenshire Council meets the full cost.

The cost of respite services for young carers is met by the Young Carers support projects.

Some service users and carers have chosen to receive **direct payments** which they use to purchase respite/short breaks. Direct payments are money given

⁵ Carers UK (2004) Young Carers in the UK: The 2004 Report

⁶ H.M.Government (1999) Caring about Carers: A National Strategy for Carers

to the service user/carer by the local authority in order that the person arranges and buys services themselves. The monies can only be given after an assessment decides that the person needs community care or children's services.

As direct payments can potentially offer more flexibility and choice service user and carers are increasingly looking at this option.

The present situation

Currently the majority of Aberdeenshire's respite/short breaks services are residential in nature, although, there has been some increase in the availability of day care and sitter services, which can provide shorter breaks.

It must be noted, however, that the range and quality of breaks available is, in part, determined by the **user group** to which the cared for person belongs. This results in inequitable provision to different groups of carers and is an aspect which we need action to address.

Carers have raised concerns about the range, location, availability and flexibility of respite resources particularly in terms of the types of residential resources available to older people and people with learning disabilities. A carer attending the South Aberdeenshire Forum⁷ said of respite services:

"..totally inappropriate; totally inflexible; totally unresponsive; definitely not enough."

Whilst not all views of current respite provision are as negative it is evident from speaking to carers across Aberdeenshire that much needs to change.

Respite for young carers in Aberdeenshire is provided from the Voluntary sector. There are young carers support workers in each area of Aberdeenshire – North, Central and South – who provide young carers with time away from their caring situation by organising group activities and individualised support. In 2005 the funding allocated to two Young Carers Projects was substantially increased to enable further development of the service.

⁷ South Aberdeenshire Carers Forum, South Aberdeenshire Carers Support Project, June 2005

SECTION 6 – CARERS INVOLVEMENT

Introduction

Aberdeenshire Carers Strategy recognises that there is great value in involving carers as equal partners in the planning and development of services that affect their lives.

Working in partnership with carers is a theme contained in the National Strategy for Carers in Scotland and has been the central focus of the Joint Futures for Carers – Making Local Partnerships Work project.

What is the mechanism for planning and developing services?

The Aberdeenshire **Carers Strategy Implementation Group** is responsible for directing planning and identifying how services should be developed and delivered in line with local and national strategies.

The CSIG has representatives from Social Work, Health, the Voluntary sector, respite providers and carers.

The group operates through joint meetings and meetings of the four sub-groups which deal with operational issues, development, funding and strategy review.

Recommendations from the group are fed into the Health and Community Care Executive and Children's Executive which oversee planning and development in Aberdeenshire.

Present situation

This Strategy acknowledges that Aberdeenshire has a number of well established carers organisations, carers groups and forums, where carers views are sought. However, carer involvement in planning and developing services **remains very limited.**

The CSIG described above struggles to recruit and retain carers and of those carers who have been involved there is poor representation from carers of older people, those with mental health problems and carers from minority ethnic communities.

We also acknowledge that the views of young carers are at present represented by young carers support workers. Engagement of young people in planning and development of services also remains very limited.

SECTION 7 – SUPPORT FOR CARERS

Introduction

The **whole** of this Strategy is about supporting carers more effectively in their caring role. However, in this section we discuss the kinds of direct support services and resources that are currently available within Aberdeenshire and the further action that is required.

Carers undertake a diverse range of tasks for which they require appropriate support. Carers have identified that they want support that is flexible and reliable, including having access to practical as well as emotional support. The provision of information, advice, training and equipment is considered vital if they are to continue to care and maintain their health and well-being.

Research evidence strongly suggests that carers benefit from contact with other carers in similar situations to their own. Such contact provides information about services, about how to cope with caring and the reassurance that carers are not alone in feeling the stresses and strains of caring. As one carer⁸ said:

“I would like to have more social meetings with other carers on a regular basis....To speak and hear from others who know what I am going through and can share feelings and experiences”

Of course, such groups may not be appropriate for every carer and it is important to continue to offer individual support as well wherever possible.

Training is another important area of support that can empower carers. Research shows that training can provide carers with new skills and confidence, allowing them to continue to care.

In developing carer support in Aberdeenshire we also need to be aware that carers in rural areas can face particular difficulties. These include travel/transport problems, lack of choice of local services and limited access to information.

Present situation

Although carers' support is provided by a number of different agencies, including Social Work and Health, it is the **Voluntary sector** which has the central role in service provision. Many of the carers support projects and services across Aberdeenshire are funded by Aberdeenshire Council through the Carers Strategy budget (see Section 10). Others are funded through the Council's Grants to Voluntary Organisations.

Carers Centres – There are currently three carer's centres in Aberdeenshire - Peterhead , Fraserburgh and Banff Aberdeenshire carers are also able to access the Aberdeen Carers Centre. In Central and South Aberdeenshire there are no carers

⁸ Spring into Summer: Carers Event, NE Aberdeenshire Carers Centre, April 2005

centres but there are carers projects offering similar services.

Carers' projects – There are a number of carers' projects in Aberdeenshire providing both generic and specialist carers support. There are young carers projects in all parts of Aberdeenshire.

(see Appendix 3 for a list of key centres and projects)

Form of support – Most of the carers' projects run support groups as well as offering carers 1:1 support. Additionally, Social Work and Health staff provide 1:1 support for carers and sometimes offer advice and support to groups.

Many carers have said they would prefer more 1:1 support. Some carers have said it is difficult to access groups.

It is acknowledged that in a rural area like Aberdeenshire resources, particularly staff time, have an impact on the range and frequency of services which can be provided.

Welfare rights advice – The Aberdeenshire Advice Services Network operates advice agencies in 9 sites across Aberdeenshire. Advice to carers is also provided through the carers' projects and from Social Work, Health and Department for Work and Pensions staff.

Training – Some carers have access to training, for example, through the Joint Learning Disability Training Project and other training sessions are offered through Voluntary organisations, Social Work and Health. The

availability of training is variable and there is not a consistent strategy for offering training to carers.

Practical support – Supports such as Home Care, transport, day care and housing support can be provided through Social Work following an assessment of need for the cared-for person. Such supports can relieve pressure for carers by taking away some of their caring responsibilities.

Social Work and Health both have remits to provide equipment following an assessment of need for the cared-for person.

Practical assistance along with short break services (described in Section 5) can help to support carers who wish to remain in employment.

Support in an emergency – Many adult carers worry what will happen to the person they care for if they are ill or if they have to respond to some kind of urgent situation. Many young carers worry what will happen if they are not there when their relative needs them.

Aberdeenshire Council and NHS Grampian are able to provide supports in emergency situations, although the arrangements made depend on the type of situation, the needs of the cared-for person and the resources available at that point in time.

SECTION 8 – YOUNG CARERS

Introduction

There are many definitions of 'young carer' however, for the purpose of this strategy we will use the following definition drawn up by the Carers National Association (1998):

A Young Carer is:

'anyone under the age of 18 whose life is in some way restricted because of the need to take responsibility for the care of a person who is ill, has a disability, is experiencing mental distress or is affected by substance misuse.'

Children and young people taking on caring roles live in diverse circumstances and family situations. Like other groups of carers, young carers' experience of caring is an **individual** one. However, young carers take on caring tasks that are the same as those taken on by adults (see page 5) and a significant percentage provide care for more than 20 hours per week. A report in 2004⁹ found that 82% of the young carers interviewed were providing emotional support, 48% were providing general medical and nursing care and 18% were providing intimate care.

At least 2.5% of all family carers in Aberdeenshire are young carers

⁹Carers UK (2004) Young Carers in the UK: The 2004 Report

(2001 Census). However, as with statistics for adult carers the actual number of young carers is likely to be far higher. We believe that there are likely to be a large number of 'hidden young carers' who are currently not recognised.

Why do young carers take on a caring role?

The reasons for young carers taking on a caring role are complex. The main reasons would appear to be:

- Poor uptake of or a lack of adequate support services for their ill/disabled relatives.
- The nature of the illness/condition – its intensity, stage, duration and change.
- Poverty and social exclusion result in families having no other choice.
- An expectation that by living with the cared-for person caring responsibilities fall to young people as the person(s) nearest at hand.

Children first?

This Strategy recognises that young carers will have needs similar to all children, but many may have additional needs related to their caring role.

Some young carers want to be seen as children/ young people first, whilst for others the foremost issue is that of being a young carer. In line with the Scottish Executive approach to young carers issues

this Strategy wishes to address the needs of both groups.

It has been argued that we should not be supporting young carers to care – rather we should be creating systems where the need for them to have to care is minimised. This Strategy takes the stance that young carers will always exist even though our goal is to decrease their numbers. We want therefore, to support young carers as much as possible and try to offer them choice as much as possible about their caring role.

The impact of caring on young carers

The development and emotional needs of young carers may be **compromised** as a result of taking on tasks and responsibilities that are inappropriate to their age and development. In addition, young carers may have limited opportunities, horizons and aspirations, educational problems, health problems, difficulties in transition to adulthood and employment difficulties¹⁰. Young carers also may experience exclusion and feel stigmatised.

As one young carer put it:

“I get angry about the way she is as people don’t understand and laugh at her”¹¹

The role of different agencies

A range of agencies have a responsibility for securing the well-being of children and young people. Securing well-being and protecting young people from all

forms of harm to ensure their appropriate development has been a primary aim of national policy. Local authority Social Work departments working with other local authority departments and Health have a duty to safe guard and promote the welfare of children in the area who are in need.

There is a range of legislation governing the involvement and duties of agencies such as, Health, Education and Youth Justice services. Effective collaboration between staff in different disciplines and agencies assessing children in need and their families is essential if children are to build successful, independent lives.

Young carers have a right to an assessment of their needs and to receive support -Children (Scotland) Act 1995 and/or Community Care and Health (Scotland) Act 2002). All agencies involved have duties to ensure this takes place.

The present situation

Within Aberdeenshire there are 4 young carers support workers employed by Voluntary organisations (see Appendix 3). These Young Carers projects are funded by Aberdeenshire Council through the Carers Strategy Budget.

Each Young Carers project offers young carers direct support, information, advice, counselling and respite services. Work is undertaken with young carers on an individual basis and in groups. Some projects have direct links to schools and provide drop-in services. The projects frequently

¹⁰ Carers UK (2004) Young Carers in the UK: The 2004 Report

¹¹ Dundee Young Carers Project event report “Tell it how it is” (2005)

have waiting lists of young carers requiring their support.

Within Social Work the responsibility for assessing young carers lies with both adult and children's services. Providing integrated services to young carers which have identified links between Community Care and Children's services is a challenge. This challenge has not been addressed adequately at the present time and this has resulted in few young carers having a formal assessment.

SECTION 9 – CARERS HEALTH AND WELL BEING

Introduction

“Caregiving should be recognised as a public health issue”¹²

There is now a substantial body of research evidence which shows that caring does have an impact on the health and well-being of the carer. We are using the terms ‘health and well-being’ deliberately to emphasise that health is not just about the absence of illness but is also about an overall sense of personal, physical and emotional comfort which enables a person to cope with daily life.

Many carers tend to **neglect their own needs**, including their own health needs, because they focus on the needs of the person they are caring for. Yet in the recent OPM survey¹³ 63% of carers interviewed said that caring had had some impact on their health.

How does caring affect health?

Hirst¹⁴ found that caregiving was more often associated with emotional and mental health problems than physical health problems. However, he noted that carers risk physical injury through undertaking tasks such as lifting

and handling and risk susceptibility to infection due to, for example, suppressed immune systems.

Hirst’s research found that carers had an increased risk of health problems if they were heavily involved in caring tasks and if they were caring for someone in the same household. The emotional distress of caring was found to increase with the closeness of the relationship between the carer and cared for person.

The study found that carers who had received training in basic nursing and rehabilitation skills were able to cope better, reported a better quality of life and had improved emotional health. This enabled the carer to carry on caring.

Another important finding of Hirst’s research was that the carers’ health was significantly affected at the key transition stages in caring. This included the beginning stages of caring and in the period after caring had ended.

The health and well-being needs of young carers have not been studied as extensively but it is clear that young carers are affected by caring. It has been argued the health needs of young carers need to be looked at specifically and that

¹² Hirst, M. (2004) Research summary – Hearts and Minds: The health effects of caring, SPRU

¹³ Office for Public Management/Scottish Executive (April 2005) Draft report – Future of Scottish Unpaid Carers: National Household Survey – Main findings.

¹⁴ *ibid* 11.

policies need to reflect the distinct issues faced by young carers¹⁵.

Some of the **causes** of poor health and well-being for carers include¹⁶:

- Lack of appropriate support
- Isolation
- Financial stresses
- Lack of information

Putting caring and health on the agenda

In chapter 5 of the recently published Kerr Report¹⁷ the vital role of unpaid carers in the provision of health and social care is recognised. The report makes five key recommendations for the NHS specifically in relation to the needs of carers. This Strategy would endorse these recommendations:

1. Makes carers' health a public issue
2. Implement fully the NHS carer information strategies
3. Encourage carer participation and partnership involvement in planning
4. Develop and provide carer training
5. Build 'carer awareness' into professional training

NHS Grampian in partnership with carers, Aberdeenshire Council and Voluntary sector agencies will work towards the implementation of these recommendations.

Tackling stigma

Earlier in this section reference was made to the emotional impact of the caring role. This Strategy recognises that stigma and discrimination are important factors affecting our emotional well-being, and that such factors are very often overlooked.

Carers may experience stigma and discrimination for a number of different reasons. It is important that we recognise and address discrimination whenever it occurs. Carers, like other people in society, can experience discrimination on the grounds of age, disability, gender, sexual orientation, status, race, ethnicity, religious or political beliefs.

In addition, we recognise that carers can experience specific forms of discrimination related to both their role as a carer and by their association with the person they care for.

The nature of the caring role can lead to carers being devalued by others. As these quotations show:

"I've given up my whole life. I want to be recognised. The authorities should recognise me. When I go to the hairdresser they ask me is this your day off? When I say no, I care for my son, I am made to feel lazy, like I am not able to work. The public needs to be educated as well"¹⁸

"Being a mum-carer you do not get all that much respect..."¹⁹

¹⁵ Warren, R. Conference presentation – Carers Health – Working for a Positive Future, 6th October 2004, Edinburgh

¹⁶ Carers UK (2004) In Poor Health

¹⁷ The Kerr Report: Building a health service fit for the future (2005), NHS

¹⁸ Office for Public Management/Scottish Executive (April 2005) Draft report – The Future Needs of Unpaid Carers – Final report

¹⁹ Chesson, R. (2003) Who's there for carers?, MS Society Scotland

Carers have also experienced what is known as 'discrimination by association'. This can sometimes refer to situations where carers face a similar type of discrimination as the person they care for:

Many of the supports and services described in other sections of this Strategy contribute to carer well-being.

"The stigma attached to mental health problems means people just don't know how to deal with it. I feel like my whole life is encompassed by my caring responsibilities. I just want to be treated normally"²⁰

This form of stigma can also refer to situations where carers feel very vulnerable because of the care they provide. It is often a particular issue for young carers who are made to feel very different from their peers and who may be teased or bullied about the medical condition of their parent, sibling or other family member.

This Strategy welcomes the work being undertaken by the Grampian Anti-Stigma Campaign who have included in their objectives working with and supporting carers in the context of stigma and discrimination.

Present situation

The health needs of carers are primarily met through Primary Care services, such as contact with GPs, Community Nursing staff and professions allied to medicine.

The wider well-being needs of carers are met through a variety of agencies including Health services, Social Work and the Voluntary Sector.

²⁰ Office for Public Management/Scottish Executive (April 2005) Draft report – The Future Needs of Unpaid Carers – Final report

SECTION 10 – FINANCIAL FRAMEWORK

Introduction

This section of the Strategy outlines the allocation of funds for carers' services in Aberdeenshire in 2006/2007.

It is important to note that identifying the funding for carers' services is complicated by the fact that the majority of support and services are associated with other Community Care and Children's budgets. For example, care management and social work budgets used to fund respite services, care at home and transport.

There is one specific budget which is identified to support carers and this is the Carers Strategy Budget

Carers Strategy Budget

This budget is available on an annual basis to support carers initiatives provided by the voluntary sector. The priorities for funding are set by the Carers Strategy Implementation Group. The Finance sub-group makes decisions about funding awards. Membership of the CSIG is attached at Appendix 3.

Total Budget 2006/2007 - £396,000

<u>CATEGORY</u>	<u>FUNDING RECEIVED</u>	<u>PERCENTAGE OF TOTAL</u>
Carer support (including some elements of training)	£210,180	53.1%
Young Carers support	£119,163	30.1%
Support to local voluntary organisations	£61,934	15.6%
Other	£4,733	1.2%
Totals	£396,000	100%

APPENDIX 1

MEMBERSHIP OF THE CARERS STRATEGY DEVELOPMENT WORKING GROUPS

Date of working group	Name	Role
2002 - 2003	Andrea Hauxwell	Young Carers Support Worker, Aberdeenshire Central Project
	Gaye Morrison	Strategic Development Officer, Aberdeenshire Council
	Moira Steinbach	Carers Support Worker, Aberdeenshire North Project
	Christine Stewart	Carer
	Jan Wells	Manager, Aberdeen Carers Centre
	Rieta Vilar	Joint Future Planning Manager (NHS Grampian – Moray)
2005	Lynn Boyd/ Rieta Vilar	Joint Future Planning Manager (NHS Grampian – Aberdeenshire CHP)
	Jill Brannan	Strategic Development Officer, Aberdeenshire Council
	Shona Cormack	Young Carers Support Worker, Aberdeenshire North Project
	Andrea Hauxwell	Development Officer, K & D Voice
	Moira Steinbach	Carers Support Worker, Aberdeenshire North Project

APPENDIX 2

LEGISLATIVE FRAMEWORK

The **Social Work (Scotland) Act 1968** places a duty on the Local Authority to promote social welfare by making advice and guidance available. Additionally, if it appears to the Local Authority that the carer being assessed would be entitled to community care services then the carer could be assessed under the Social Work (Scotland) Act or NHS and Community Care Act 1990.

The **Disabled Persons (Services, Consultation and Representation) Act 1986** places duties on the Local Authority to make an assessment where it appears that the carer being assessed is a disabled person.

The **NHS and Community Care Act 1990** set the framework for the implementation of community care policy and procedures and established support for carers as a national priority.

The **Carers (Recognition and Services) Act 1995** entitled some carers to a separate assessment and indicated that carers should be recognised and valued as key partners with other care-providers.

Under the **Children (Scotland) Act 1995** if it appears to a Local Authority that the young person involved in a caring role has support needs or is at risk of inappropriate caring they should be regarded as a 'child in need' and assessed.

The **Education (Additional Support for Learning) (Scotland) Act 2004** places duties on Local Authorities to provide learning support for any child/young person who may need this irrespective of cause.

APPENDIX 3

LIST OF CARERS CENTRES AND CARERS PROJECTS IN ABERDEENSHIRE

Within this appendix it is not possible to provide an exhaustive list of all the groups within Aberdeenshire that provide carers with support. We have aimed to list the key generic projects and the Carers Centres, as we are aware that these organisations can signpost carers to other sources of support/specialist carers support services. We have included the contact details for Grampian Care Data as this is a key source of information for carers and again can provide effective signposting so that carers are put in contact with groups/agencies that can be of assistance.

Carers Centres:

Aberdeen – VSA Carers Centre, 22 – 24 Belmont Street, Aberdeen, AB10 1JH Tel: 01224 646677

Banff – VSA Carers Centre, 15 Fife Street, Banff, AB45 1JB Tel: 01261 812300

Peterhead – (including Young Carers) VSA Carers Centre, 5 North Street, Peterhead, AB42 1JS Tel: 01779 490894

Fraserburgh – Crossroads Carers Centre, Saltoun Chambers, 19 Seaforth Street, Fraserburgh. AB43 9 DB Tel 01346 510280

Carers Projects:

Huntly – (including Young Carers) Gordon Rural Action Carers Project, 55 Gordon Street, Huntly, AB54 9EQ Tel: 01466 793676

Inverurie – (including Young Carers) Gordon Rural Action Carers Project, 15A High Street, Inverurie, AB51 3QA Tel: 01467 625277 or Tel: 01467 629955 for Young Carers project

Stonehaven – (including Young Carers) Carers Project, c/o Crossroads Carers Centre, 44 – 46 Barclay Street, Stonehaven, AB39 2FX Tel: 01569 766714 or Tel: 01569 766986 for Young Carers project

Grampian Care Data:

Website: www.grampiancaredata.gov.uk

Tel: 01651 872727

Information 0800 136 225

line:

Minicom: 0800 136 225 (Text phone)

E-mail: caredata@aberdeenshire.gov.uk

Address: C/o ALIS, Meldrum Meg Way, Oldmeldrum, INVERURIE AB51 0GN

APPENDIX 4

MEMBERSHIP OF THE CARERS STRATEGY IMPLEMENTATION GROUP

Douglas Boynton (Chair)	Aberdeenshire Council
Jill Brannan/ Sheena Swinhoe	Aberdeenshire Council
Shona Cormack	Voluntary Service Aberdeen
Marion Cruickshank	Deveron Care
Angelika Eberhard	National Schizophrenia Fellowship
Elizabeth Eyre	Crossroads
Amanda Hampton	Gordon Rural Action
Andrea Hauxwell	K and D Voice
Kevin Hutchens	Aberdeenshire Council
Gill Kitching	Aberdeenshire Council
Rosie Leavett	Age Concern Scotland
Brenda Ledger	Voluntary Service Aberdeen
Marion Lorimer	Take-a-Break
Stuart McCutcheon	Gordon Rural Action
Alison McLaughlin	Gordon Rural Action
Anne Naylor	Alzheimer Scotland
Anne Park	Voluntary Service Aberdeen
Marion Sievwright	Gordon Rural Action
Moira Steinbach	Voluntary Service Aberdeen
Maureen Stephen	Bridge CVS
Aine Stewart	Voluntary Service Aberdeen
Rieta Vilar	NHS Grampian
Jan Wells	Voluntary Service Aberdeen
Jenny Whinnett	PAMIS, Carer

COMMENTS ON THE DRAFT STRATEGY

The draft Aberdeenshire Carers Strategy was circulated for consultation from November 2005 to February 2006. A small number of responses were received. Overall, the draft strategy was seen as being well presented, clear and easy to understand. Issues identified from the draft were as follows:

- An agreement that there is a need to raise awareness of the Carers role as many people, eg parent carers and young carers do not identify themselves as carers
- A request that carers be better involved and informed when cared for relatives are being admitted and discharged from hospital
- A concern about the number of times carers are consulted about various issues and the need for consultation to be more targeted to appropriate carer groups
- An agreement that Direct Payments offers a good alternative for carers and the need for staff to be able to offer accurate information to families on this.
- A need for more respite resources to be available locally
- Unmet needs to be identified and actioned within an appropriate time scale
- An acknowledgement of the valuable role undertaken by the Carers Support Workers