

NHS GRAMPIAN

Carers Information

Strategy

2007 - 2010

A strategy to identify people who are unpaid carers, and to ensure that they have the information and support they need.

A carer is a person of any age, or gender who, unpaid, provides help and support to a relative, partner, friend or neighbour who could not manage to live independently without that because they are frail, have a long-term illness or disability.

It is important that such unpaid carers are not confused with paid care workers

August 2006

Do you have difficulty understanding the English language?

If you have a problem reading or understanding the English language, this document is available in a language of your choice. Please ask an English speaking friend or relative to phone, write or email Nigel Firth, Equality and Diversity Manager, NHS Grampian. His contact details are:-

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NHS GRAMPIAN CARERS INFORMATION STRATEGY 2007 - 2010

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1.0 Introduction

NHS Grampian's Carers Information Strategy has been produced by building on work carried out in 2004 when a draft discussion document was prepared after extensive consultation with carers in the Grampian area. This strategy has again called on carers throughout Grampian to assist in developing a Carers Information Strategy that will recognise the minimum standards set out by the Scottish Executive, taking into account their recommendations on good practice and reflecting the views, needs and issues affecting carers in Grampian. It has been noted that there is often confusion between informal carers and paid care workers. *This strategy document refers to informal carers who care for relatives, partners, friends or neighbours and who are unpaid. Professional paid care workers and family members looking after children without disabilities or long-term health conditions are not included in the definition of carer, as used in this strategy.*

Carer involvement is an evolutionary process which when secured to the PFPI agenda both enables the identification of carers and promotes existing carers issues and their involvement in change.

Carers are defined in legislation as people of any age who provide a substantial amount of unpaid care on a regular basis. Many people carrying out a caring role do not see themselves as carers, only seeing themselves as a parent, child, wife, husband, partner, friend or neighbour. Many carers tend to be 'hidden' in our communities and are not aware that help and support is available. Carers may live with the person that they care for, but many do not. Some carers will be balancing caring responsibilities with paid employment. Many give up paid employment to care. There is no such thing as a 'typical' carer. Caring has an impact not only on individual carers, but also on whole family units, friends, colleagues and employers.

There are currently estimated to be 670,000 carers in Scotland, representing 16% of the population. As a result of advances in medical treatments and improved health technology people all over Scotland are becoming healthier and are living longer. Many more people with complex needs are being cared for at home and for longer periods. Accordingly, predictions for the future indicate that in the next 10-20 years our population balance will change and we will have an increase in the numbers of older people who will require care at home and in the community. All these factors combined indicate that there will be an increasing number of young carers, parent carers and older carers who are experiencing changes in the types of caring they provide.

The Scottish Executive and NHS Grampian increasingly acknowledge the considerable contribution of unpaid carers in Grampian. Carers throughout Scotland are currently estimated to save the public purse in excess of £5 billion per annum by providing unpaid care to friends, family members and others. Clearly, if unpaid carers could not provide this level of care, health and social care systems would be unmanageable. If carers are no longer able to provide care because of their own ill health or lack of support for the caring role, the existing pressure on statutory services will be significantly increased.

Recent findings published by the Office for National Statistics offer worrying evidence of the long and short term detrimental impact of caring on the health of carers. It is worth noting that:

- ♦ Three in five (3 in 5) people will take on a caring role in their lives
- ♦ 39% of carers tell us that their mental or physical health has been affected as a result of caring. This amounts to an estimated 253,000 carers in Scotland
- ♦ There are high incidences of stress, depression and musculo-skeletal problems among carers
- ♦ 14% of carers report that they smoke, drink or use drugs more as a result of their caring responsibilities. This represents an estimated 91,000 carers in Scotland.
- ♦ Carers focus on the health and wellbeing of the person, or persons, they care for to the detriment of their own. A proactive approach to the carers' health is therefore essential.

NHS Grampian is aware that while fulfilling their invaluable role, the needs of carers themselves for support and for information may all-too-easily remain hidden. The importance and benefits of recognising and meeting these needs cannot be underestimated.

The Scottish Executive positively acknowledges the need to support carers both through their guidance to statutory authorities on the implementation of the Community Care and Health (Scotland) Act 2002 (see Sections 8-12: Carers – Guidance) and this strategy.

Health professionals have ready access to, and have a unique opportunity, to identify people who are carers and to ensure that they are supported and provided with appropriate information at the earliest stage of their caring role. This early identification also facilitates the opportunity for health professions to work in partnership with carers in their role as a 'key partner in care' as defined in the above Act. The benefits that can be gained by such a working relationship are immeasurable for health professionals, patients and their carers.

Joint Carers Strategies in each of our three local authority areas (Aberdeen City, Aberdeenshire and Moray) already provide the framework for supporting and involving carers across Grampian.

While we have much good work to build on in Grampian, we also face many challenges in terms of our ageing population, the increase in long-term health conditions, and also in identifying and supporting the many young people who are carers for other family members, affecting their childhood experience.

We must also be aware that Grampian is undergoing its biggest population change ever. Currently, there are approximately 1,200 migrant workers and families coming to live permanently in Grampian each month. Most of the migrant workers and families are from Eastern European countries. At present, most are relatively young, however, in

future, it is possible that some may choose to bring over their dependent parents, so that they can benefit from the improved healthcare available in this country. This may increase the numbers of carers in Grampian significantly.

This strategy aims to bring together - and build on existing good practice - the many pieces of ongoing work, to identify people who are carers, and to support them, especially in terms of the information they need, both for their caring role and for themselves.

NHS Grampian's local commitment to developing such a strategy is also set against a background of national policy. Within the Community Care and Health (Scotland) Act 2002 there is a requirement in section 12 for NHS Boards to produce a strategy to promote the identification of carers and meet their needs for information.

This Carers Information Strategy is required to be endorsed by NHS Grampian Board prior to being sent to the Health Minister for approval by 31st December 2006

This strategy will form an integral part of the NHS Grampian's Corporate Communication strategies. In its local implementation it sets the minimum standards to support the local objectives to be taken forward through future Joint Health Improvement Plans and the Carers Strategy Groups in each of the three Community Health Partnerships in Aberdeen City, Aberdeenshire and Moray and in consultation with local carers groups and organisations.

2.0 Why do we need a strategy?

Over the last ten years there have been many changes and developments in the fields of both medical and social care. Alongside this has been strategic direction of 'Care in the Community' which is reflected in the underpinning legislation and policy introduced in recent years.

Demographic change will mean a significant growth in the number of older people requiring care and support in their own home. Already many carers, with significant caring responsibilities, are older people themselves looking after partners, husbands, wives, children and grandchildren within their own communities, and consequently much more help, care and support is and will be needed to support in the domestic setting.

There is also a growing awareness that many more parent carers of all ages (who often experience the longest caring role) are providing not only more care, but also more complex care within the home.

The vital contribution provided by carers in the community will continue to increase in value as Local Authorities, the NHS and other agencies strive to redesign service provision to meet emerging need.

As the number of people requiring care is set to rise, social trends appear to indicate a decrease in the number of potential carers in the future. Extended family networks, which in the past supported those who had care needs, are becoming less common. This reinforces the need to support those carers who are able and prepared to take on the responsibility of family members and friends who require their help.

There is an increasing recognition of the effects on a person when they take on a caring role. These include physical, practical, emotional, financial, employment, social, health and wellbeing issues. These effects can be even greater for carers in the local ethnic communities who also face possible communication barriers leading to greater social isolation. There are also many carers who are themselves suffering from illness or disability. We know that providing information and support is an effective way to help both patients and carers to minimise the negative effects of their situation and the caring relationship.

A range of legislation and policy underpins the recent development of carers support services, and also highlights the role of both social work and healthcare professionals in identifying people with a caring role, and ensuring that they have the information they need at the time they need it. (Appendix 1)

3.0 Why do we need to identify carers?

NHS Grampian recognises that there are many reasons why we should identify carers, including:

- Carers have a right to have their own health and social care needs met.
- More than 670,000 people in Scotland are unpaid carers. In Grampian over 40,000 people are unpaid carers. Recent research suggests that three out of every five people will take on a caring role at some time in their lives.
- Most people do not recognise their caring role, seeing only the relationship with the person for whom they care e.g. “I’m just her sister”. Many patients are themselves carers. Many hospital visitors are – or are about to become – carers. It is important to help people recognise that they are a carer, and ensure that they can access services to support them in this role.
- The relationship between health and social work professionals and carers is both personally and professionally important, defined in law as ‘partners in care’. Such partners can gain from each other’s knowledge of the situation to ensure that a holistic approach is taken for both patient and carer.
- Carers provide a wide range of services that enable people to remain living at home or in the community. If carers reach a point where they are unable to continue in the caring role for whatever reason, there are implications for healthcare services, as well as for the individuals and professionals involved. One study¹ reported that 51% of carers had suffered a physical injury (e.g.

² where 93 carers were studied, 32% felt that their health was affected by caring; 63% reported stress and 47% reported depression. 90% of carers' report sleep disturbance.

- Many carers cope well with their caring responsibilities and require little or no support. Carers' needs frequently change and it is essential that health professionals adopt methods to ensure carers are identified early on in their caring role and provided with appropriate information on sources of advice and help available to them throughout the caring experience, with additional support at times of transitions.
- Too many carers are not aware that support, financial and practical, may be available until they reach crisis point, a point at which their own physical and mental health can already be damaged.
- For health staff, being 'carer aware' in recognising, acknowledging and working collaboratively with carers as an integral part of their routine could have significant benefits for them as well as for the patient and their carer.

DID YOU KNOW?

The financial cost to replace existing 'informal unpaid care' in the UK is accepted as £57 billion per annum. This matches the cost of existing NHS services in the UK.

If 2% of existing unpaid carers could no longer fulfil their role then the effect on health and social services would be highly significant

4.0 What information should be available?

NHS Grampian acknowledges the advantages of recognising and treating carers as Key Partners in the provision of care. We will:

- Work in partnership with carers of all ages, local authorities, the voluntary sector, the private sector and others to provide information to carers as early as possible within the care journey.
- Provide free to carers, who appear to be a person who may have rights under section 12AA of the social Work (Scotland) act or Section 24 of the Children's (Scotland) Act the information that they may have these rights.
- Provide information at each stage of contact in a range of formats or languages, at all stages of contact, enabling carers to access information irrespective of their age, disability, ethnicity, gender religion/faith, sexual orientation or other specific needs. We will recognise that carers with a disability, as described in the Disability Discrimination Act 1995 and the 2006 Disability Equality Duty, will have additional rights.
- Inform carers of their potential rights for the opportunity of having a Carers Assessment under the Community Care and Health (Scotland) Act 2002 and to direct carers to appropriate sources of information and practical support.
- Promote carer awareness amongst all levels of NHS staff whether employed by or contracted to the NHS ensuring that all staff are able to identify and signpost carers, as routine practice, to local/national as appropriate, Carer or condition specific information. Referrals to Carer organisations are to be developed in line with NHS protocols and local referrals. These referrals need to comply fully with the data Protection Act and confidentiality of information.

Outcomes

For carers this will mean that:

- Carers are identified earlier in the care journey
- There will be raised awareness and appreciation of the caring role in the 21st Century
- Carers are informed and fully involved and may influence the process and decisions taken in relation to hospital admission and discharge
- Information will be available to help recognise those who carry out a substantial and regular role as a carer.
- Information will be made accessible in all health settings about carers self and statutory assessment and how to access these.

- Carers will be routinely informed and offered information about support services that are available locally, in the language or format of their choice
- Information tools are available to keep carers 'connected' and up-to-date, such as newsletters, again offered in the language or format of their choice
- Carers health and wellbeing is of equal importance to that of the cared for person

For health professionals and multi-disciplinary teams this will mean:

- Health professionals within NHS Grampian have a responsibility to identify and inform carers and be aware of how to access appropriate information for carers of all ages
- There will be a more comprehensive understanding of the caring role, its responsibility and effects on the life of a carer of any age
- Understanding and recognising the caring role will enable all concerned to share the mutual benefit of working with carers as 'key partners in care'
- Information on how to access information for carers will be available locally enabling health staff to refer or signpost carers to local support
- The information provided will also be sensitive to the cultural needs of carers and those being cared for.

For NHS Grampian this will mean:

- Carer awareness will be an integral part of strategies and policies and training will be developed that will be more carer aware, friendly and responsive
- Information about NHS Grampian's services and services for carers will be available across the region.
- A lead person at general or senior management level who will link with the Corporate Communications Director (incorporating Patient Focus and Public Involvement) who will have responsibility to ensure effective development and implementation of this strategy will be identified.

5.0 Policy background

NHS Grampian, along with partners in Social Work and the Voluntary Sector, recognises that involving and working with carers as key partners in providing care is a priority for the Scottish Executive. This is reinforced by the Executive's commitment to social inclusion and equality and is an integral part of wider policy approaches which are shaping the way that health and social care services are delivered.

Policy and legislation has taken account of carers since 1995 (Carers Recognition and Services Act 1995) when a UK-wide Strategy was published. This strategy contained 70 recommendations that can be grouped into:

- Improved information for carers

- Access to assessment and support
- Recognition of the carers' role by health and social care staff
- Acknowledgement of the needs of young carers

A *Strategy for Carers in Scotland* followed this in 1999, and was the Scottish Executive's first national strategy. As a result most of Scotland's local authorities developed joint strategies which mirrored the aims of the national strategy, and included local needs and actions.

In 2002, the Community Care and Health (Scotland) Act 2002 was produced. Scottish Executive Circular CCD2/2003 provided guidance on implementing the provisions of the 2002 Act concerning unpaid carers. It expands on the requirement in the 2002 Act for all NHS Boards to prepare and submit a Carers Information Strategy (CIS).

To ensure that “regular and substantial carers”, including young carers, have all the information they need on sources of advice and support, and are aware of their right to an assessment of their needs as a carer, under Section 12AA of the Social Work (Scotland) Act 1968, and for young carers under Section 24 of the Children (Scotland) Act 1995. “

NHS Grampian acknowledges that young carers, though not “key providers” under legislation, will be engaged and consulted with in future developments including this strategy

The function of the Statutory Carers Assessment is to:

- acknowledge the caring role by both professionals and carer
- assist carers to consider the help they provide, their needs, and the needs of the person being cared for
- provide an opportunity for discussion about services which are available
- identify areas where there are gaps in services, highlighting unmet need

Some local authorities offer Carers Self-Assessment, an anonymous questionnaire to help those who are looking after someone to analyse and measure their input and role and to consider the effect it has on them. This can also be used as a request for information and/or support. The information, when collated, can inform and assist future service planning.

Additionally, the evidence to support the need to identify carers, provide them with appropriate information, support them in their caring role and encourage them to attend to their own health and wellbeing, is growing. This is being documented by carer organisations such as Carers UK whose research tells us that carers in Scotland providing high levels of care are one third more likely to suffer ill health than a person who does not have a caring role.

CARERS SAY: *“Every carer should have information on how to access and where to go for advice and information about their caring role.”*

“Taking on a caring role can be demanding and stressful as well as rewarding.”

NHS Grampian is determined to provide a local health service that proactively encourages and supports carers to maintain and improve their health wherever possible.

6.0 Caring and health

In recent years “Carers and Health” has been high on the agenda of national and local organisations.

The relationship between caring and the individual’s health is complex. The caring role is taken on in addition to other roles in the carer’s life, in response to the health problems of another person. Most carers tend to neglect their own health problems as they focus on the needs and health of the person they care for.

We all have a responsibility to ourselves to maintain and hopefully improve our health in any way we can. Carers however have additional responsibilities which alters priorities and self care.

It’s important for carers to:

- remember to take care of themselves, and have information and support to help them do that
- make an appointment to see a health professional if they have signs or symptoms of ill-health
- make sure that their doctor, and other health professionals, are aware of existing and changing caring responsibilities
- know that if they are non-English speaking or have a limited command of English, that they will have the right to have a “face to face” interpreter present or have access to “Language Line” telephone interpretation services, when meeting with a doctor or other health professional
- feel able to raise the issue of respite with health and social work staff
- find out about local carer support services
- have access to training in practical issues such as “moving and handling” and first aid

Health Improvement policy focuses on maintaining existing levels of ‘wellness’ and encourages improving health where possible through informed lifestyle choices. Raising ‘Carer awareness’ among both the general public and health professionals will help to ensure that carers can be advised and assisted in maximising their good health and managing their lifestyle to enable them to maintain and improve their health and wellbeing.

DID YOU KNOW? In areas where carers receive good support, GPs write out fewer scripts for anti-depressants.

Barclay’s Reseach 2001

CARERS SAY: *“The health of carers should be a priority for the NHS – if we get ill then the health services have to take over.”*

7.0 What does our strategy aim to do?

NHS Grampian's aim is to ensure that carers have access to appropriate information at the right time and that 'best practice' is shared across NHS Grampian. It is vital that we build on existing successful work and fill any gaps in our service whilst continuing to develop flexible working practices that best serve carers' need for support and information.

NHS Grampian will:

1. Develop consistent mechanisms to identify carers of all ages early in their care journey and to mainstream these into everyday working practices.
2. Create an environment where carers are actively consulted, involved and empowered in the decision making process.
3. Ensure that carers are aware of their right to a statutory assessment
4. Put in place protocols and actions that will help improve the health and wellbeing of carers and patients
5. Ensure that across NHS Grampian appropriate information is available to all carers, in different languages and formats.
6. Increase partnership working at all levels with carers and with carers organisations recognising the immense benefits of such partnerships
7. Promote awareness amongst all staff of the issues important to carers and provide ongoing training to develop further understanding of these issues
8. Provide support for staff who are carers through greater awareness of the needs and issues involved when carers are also employees
9. Develop robust procedures to identify, provide appropriate information, and support parents /young carers and to promote staff awareness of their particular needs
10. Work closely with all agencies to ensure that information passed to carers is up-to-date and relevant to their circumstances
11. Develop strategies and policies that are 'carer friendly' ensuring that this also becomes integrated into the review of existing policies
12. Develop a clear understanding of the difference between carers and care workers
13. Adopt the recommendation in *Building a Health Service Fit for the Future* by making carers' health a public health issue.

14. Ensure that all identification, information and support is respectful of carers cultural backgrounds, ethnicity and diversity.
15. Integrate carer awareness into all professional training
16. Access local training and initiatives such as a national Expert Carer Training programme
17. Focus on the health of unpaid carers by working in collaboration with local and national partners to achieve equity of support across Grampian and in line with national developments
18. Ensure that the principles and goals expressed in the NHS Grampian Carers Information Strategy are promoted and integrated into normal working practice of both staff and those contracted to the service within the acute hospital setting and across the community in Grampian
19. Ensure that where conflict is apparent in the needs of carers and patient, e.g. hospital discharge, mediation processes are fully explored.
20. The carer will be provided with the fullest information on matters likely to have an affect on them. Where conflict exists, the information will pertain only to the caring role
21. Ensure that all community health providers, including GPs and Pharmacists are informed of and engaged in supporting the NHS Grampian Carers Information Strategy
22. Recognise the Royal College of Psychiatrists' Code of Conduct on issues related to caring when this is available.
23. Provide summarised information for carers outlining what they can expect from the introduction of the NHS Grampian Carer Information Strategy
24. Further develop the Action Plan designed to achieve the objectives set out in this document, including baseline information, performance indicators and measurable qualitative data. To regularly monitor and evaluate the progress and success of the plan, recommending and making adjustments to enhance wherever possible the quality of our support for and relationship with carers

8.0 What benefits will our strategy bring?

8.1 Benefits for carers

- Improved self-esteem and coping skills in their caring role

- Improved health: mental, physical and emotional wellbeing
- Better relationship between NHS staff and carers through information sharing which benefit the patient
- Increase confidence in awareness of available benefits etc

8.2 Benefits for the person being cared-for

- More appropriate and effective care, which is culturally sensitive (as background and history of patient will be better known)
- Better physical and mental outcomes
- Less stressful environment, if good relationship between staff and family
- Less likelihood of readmission to hospital (research such as “You can take him home” by the Princess Royal Trust for Carers is available to support this)
- Improved health of carer (with the benefits listed above)
- Financial benefits (as carer has better knowledge/skills of the system)
- Benefits through best use of health and social care staff

8.3 Benefits for the NHS

- Optimal use of professional resources, through informed, healthy and skilled **unpaid** carers
- More targeted use of medical expertise
- Fewer GP consultations for carers under pressure
- Less frequent ‘revolving door’ admissions
- Increased knowledge of and access to carers resources
- Fewer medication errors
- Fewer dietary and cultural issues

9.0 How will we gain these benefits?

These benefits will be gained by using and developing existing good practice.

9.1 Develop consistent mechanisms to identify carers

Examples of existing “good practice”, existing projects and initiatives:

- Details of carers are passed on by health professionals, with permission, to the Aberdeen Carers Centre or local carers project
- Hospital and GP notes are marked to indicate that the person is, or has, a carer
- An information worker visits GP surgeries to ensure that carer information is available and prominently displayed
- A carers’ self-assessment form is available from the Aberdeen Carers Centre
- Carer awareness training for health and social care staff is taking place
- Publications are produced, such as a variety of booklets and guides
- *Carers News* and local newsletters are sent to the homes of carers and disseminated across NHS Grampian

- Ongoing development of carers consultation and involvement mechanisms to inform planning and development
- At some GP surgeries, new patients are asked “are you caring for someone?”
- A discharge pack is being piloted on some wards.
- Big display boards have been produced for many GP practices, with details of local support
- Information on carers services contact details appears on pharmacy prescription bags
-

Continuing Action

Integrate the identification of carers at admission or contact, for example a health professional could routinely ask at every contact “are you a carer?” and then have a simple system to enable carers to access local sources of help.

9.2 Ensure that carers know their rights to a statutory assessment of their needs

This is being achieved through the identification processes outlined above; when this becomes routine then more carers will find out about assessment.

Continuing Actions

Integration of the identification of carers as routine practice for staff and continuing to raise awareness in local communities of the benefits of assessment

Making it easier for carers to self-assess, such as online, using the NHS Grampian website and by using our public access points such as *Healthpoints*. Requirement for *Healthpoints* to carry carer information

9.3 Ensure action to help improve the health and wellbeing of carers of all ages and patients, through future Joint Health Improvement Plans (JHIPs) and carers strategies

Some examples

- Carers of all ages are identified in JHIPs, developed by the Community Health Partnerships of Aberdeen City, Aberdeenshire and Moray, These are the local health planning documents which will drive forward the aims of this strategy
- *Healthpoints* encourage carers to come along and discuss their own health and find out about help that is available locally
- The *Carers News* newsletter regularly carries articles and contact details to help carers look after, and improve, their own health

Action

Build on existing initiatives, to include health-promoting events for carers in venues such as GP surgeries and community centres

9.4 Ensure appropriate and targeted information is easily available for carers

Examples of existing projects and initiatives:

- The local carers projects already have a wealth of information
- The NHS Grampian Information Strategy identifies the importance of high-quality and accessible information for all groups, including carers
- The Grampian *Healthpoints* in Aberdeen and Elgin are promoted as one-stop contact points for health information, supported by the free *healthline* for those who cannot pop in
- An information worker visits GPs surgeries to ensure that carer information is available and prominently displayed

Actions

Build on the existing projects to make sure that we

- have standard material easily available in all NHS premises
- encourage carers to get in touch and give us feedback on the free *healthline*
- work with partner organisations to make greater use of other venues for displaying information, such as community centres and libraries
- make greater use of inpatient and outpatient booklets for patients and carers
- use online tools, such as the new NHS Grampian website and link to the websites of local carers projects

9.5 Increase partnership with carers

Examples of existing projects and initiatives:

- A variety of groups already exist which bring carers representatives together with Community Planning and Joint Future partners, such as (in Aberdeen) the Carers Consultation and Involvement Group, the Carers Task Planning Group, Carers Forum, Carers Voices (Joint Future), Carers Strategy Groups
- Carers are invited to special events and education sessions, using Crossroads for respite

Actions

- Explore how best to build on the existing groups and networks to make sure that carers are well represented in the Community Health Partnerships
- Explore how health staff could become more involved in events and training for carers
- Use the existing mechanisms/groups to involve carers in local practical and operational issues

- Explore the feasibility of a 'carer contact point' at ARI concourse, and what that would provide

9.6 Promote awareness among staff of the issues important to carers

Examples of existing projects and initiatives:

- As part of taking forward Grampian's Joint Strategy for People with Learning Disabilities, parent carers and carers of people with autism are receiving training alongside health and local authority staff. Gaining feedback and suggestions on training issues from parents and carers is an important element of this strategy
- An NHS Grampian Learning and Development Strategy is being taken forward to develop the skills of staff in involving patients (and their relatives and carers) in individual care, the day-to-day business of NHS Grampian, and in planning for the future. This staff development strategy is being taken forward in partnership with the local authorities and voluntary organisations

Actions

- Practical help for staff to identify carers
- Incorporate the experiences of patients and carers into staff training programmes by using existing tools, such as the recently-produced audio CDs featuring the voices and stories of individual patients and carers
- Explore how staff could gain accreditation for undertaking training in carers issues
- Identify issues of funding

9.7 Promote awareness of - and support for - staff who are carers

Examples of existing projects and initiatives:

- Policies on Special and Carer Leave for Domestic, Personal and Family Reasons and a Policy on Career Breaks (including sabbatical and secondment leave)

Action

- Monitor and evaluate the use of staff employment policies on Carer Leave
- The intention to send out an anonymous carer questionnaire to NHS staff to ascertain the percentage of staff who are carers

9.8 Further improve identification and support for young carers

Examples of existing projects and initiatives:

- Progress in identifying young carers through social work, education, GPs and the joint Alcohol and Drug Action Teams.

- Aberdeen Young Carers group has become linked with the Health Warriors group of local young people who actively campaign for better services for young people
- The Aberdeen City Joint Alcohol and Drug Action Team is prioritising support for children living with drug and alcohol using adults

Actions

- Continue to build on existing work, including joint efforts by all agencies to identify that may be a hidden army of young carers
- Work with young carers themselves to ascertain how we can best support them
- Continue to develop work with young carers

10.0 Accountability and monitoring

Once the Health Minister has given approval, NHS Grampian will continually monitor progress in taking forward the actions, which are agreed in this strategy. Progress will be reported regularly to the NHS Grampian Board via NHS Grampian's Designated Director for Patient Focus and Public Involvement. A lead officer at senior manager level will be identified to promote Carer identification and information with responsibility to ensure effective development and implementation of NHS Grampian Carer information Strategy identified with NHS Grampian.

Leaders from all areas of service delivery, service user and user groups are the ideal people to identify local issues and to progress improvements in local collaborative initiatives

Our performance will also be assessed by the following processes:

- The NHS Performance Assessment Framework and Annual Accountability Review
- Our progress in taking forward the Joint Future agenda in Grampian via the Joint Performance and Assessment Framework (JIPAF)
- The performance of each of our Community Planning partnerships in Aberdeen City, Aberdeenshire and Moray.

Drawn from the carers Information strategy consultation, feedback performance indicators will be developed in line with national targets. These will be consulted on with carers partnership groups before being used to determine questions to be asked on a random sample basis, for both baseline information and performance indicators.

An important part of measuring our performance will be the ongoing feedback from carers themselves through a variety of mechanisms including the NHS Grampian feedback team; surveys conducted through the Carers Newsletters and normal communication with Carers Centres and Projects.

11.0 What is happening in Grampian?

Indicative of the 'drivers' that are already steering greater recognition, more support, and fuller involvement of carers in Grampian are several projects and policy initiatives being taken forward locally which are stimulating activity and 'good practice' giving us a solid base to build on in Grampian.

These initiatives include:

- **Carers centres and projects**, with dedicated teams and committed volunteers providing support to individual carers and ensuring that the voices of carers are heard by those who plan local health and public services
- **'Patient Focus and Public Involvement'**, a national and local policy to build a true and closer partnership between the NHS and the public it serves, as individuals and as communities
- **Community Health Partnerships** in each of our local authority areas, which bring together a local partnership of NHS, the local authority, other health-related organisations, voluntary and interest groups, and all members of our communities
- **Communication.** By March 2007, all NHS Grampian premises will be equipped with "Language Line" telephone interpretation services. All areas will have access kits and staff trained in their use.
- **Community Planning**, providing increasing opportunities for carers to become involved in working with all interested organisations to build healthy communities and continually improve the quality of life for all living in Grampian
- **Joint Future**, a more 'joined-up' way for health and social care services to work together to care for the most vulnerable people in our communities.
- **Local joint strategies**, with more opportunities to get involved in drawing up the Grampian Health Plan, local Joint Health Improvement Plans, Carers Strategies and other joint strategies.
- **Joint Alcohol and Drug Action Teams**, which are increasingly recognising the needs of children who act as young carers for the drug and alcohol using adults with whom they live.
- **Local good practice guidelines** for involving people who use mental health services – and their carers – in how those services are planned and delivered.
- A staff/carers partnership network will be established, in all sectors, to promote Carer identification and awareness with a delegated responsibility to ensure the implementation of the strategy objectives and to provide management and

- **Carers Research Partnership**, a unique grouping of carers, people who use services, those who provide services, and researchers, who work together to provide robust evidence of the needs of carers and patients, develop jointly a programme of research, and extend people's knowledge of the nature of caring and of the carers' role.

DID YOU KNOW? Grampian is the only area in the UK to have a Carers Research Partnership?

Reports on this strategy's implementation and development will be included as part of the Performance review of the PFPI committee and incorporated in the annual ministerial review.

A full review of this strategy will be completed in 2009/10 and the half-yearly reports and ongoing partnership working at local and strategic levels will inform the process. These will be available to the public, on request, free of charge in a variety of formats.

APPENDIX 1

Legislation

- Carers Recognition and Services Act (1995) first formal recognition of the term 'Carer' for people who looked after friends or relatives who needed help and support because they were ill, frail or disabled, without payment. It also introduced the right to assessment for carers.
- Community Care and Health Act (2002) Introduced new provisions to enhance existing legislative duties in areas of information, recognition and assessment. It also defined carers as 'Key Partners in Care' and service providers' who required services to resource their caring role.. The same legislation introduced free personal care to those over 65 in Scotland.
- Community Care (Direct Payments) Act (1996) gave local authorities the right to make a direct payment in lieu of the community care services the individual is assessed to be requiring. This became mandatory in the CC&H Act 2002
- Children Scotland Act 1995 (section 24.) Gives young people 'affected by disability' a right to services, now augmented by the CC&H Act which gives young carers a right to an independent assessment at any time.
- The Mental Health (Care and Treatment) Scotland Act (2003) includes the provision for more people with a mental health problem to receive treatment at home, instead of in hospital. Carers will therefore require additional information and support.
- Adults with Incapacity Act 2000. Changed the system for those who were unable to make independent decisions, and allowed carers to apply for guardianship.
- Disability Discrimination Act (1995) This places a duty on NHS boards to provide accessible information, and specific information about issues of concern for people with disabilities, including carers.
- Racial Equality Act ("Fair for All") This places a duty to ensure public access to information and services; it also covers dissemination of information
- Freedom of Information (Scotland) Act (2002) Gives a general right to the public to access all types of public information held by public bodies.

National Strategies and Policy directives

- National Carers Strategy (UK) 1999 recommendations included improved information, access to assessment and support for all carers , recognition of the carers role by health and social care staff, identifying and registering carers in medical records in primary care, recognition and services for young carers, and legislative review.
- A Strategy for carers in Scotland (Nov 1999) Mirrored the main UK recommendations, including developing local strategies and services for carers, and highlighted respite issues in a separate document.
- Scottish Legislative Review (2000) A committee including carers, representatives from carer organisations, Scottish Executive personnel, NHS and local authority members, and the minister. They identified 32 recommendations to enable fuller implementation of the strategy, and seven legislative requirements. This led to the carers section in the CC&H Act 2002.
- Local carers strategies, joint documents (NHS & Local Authority) which outline localised issues, needs and action plan for developing services for carers.
- Implementation of 'The Same as You' the Scottish Executive's Review of social care services for people with learning difficulties, and their future care and support in the community.
- Designed to Care (1997) Section 2 'Achieving Better Services for Patients' sets out requirements for provision of up to date, accurate, and locally focused information.
- Our National Health (2000) section 5, 'Involving People' sets out a change programme including development of a national information project and equality of access for all.
- Patient Focus and public Involvement (PFPI) (2001) Information is one of the four main themes, with performance standards. (PAF section 5)
- Guide to the Production and Provision of Information (2003): Guidelines for identifying and delivering health information tailored to the needs of the public.
- Scottish Executive Circular CCD2/2003: Guidance on implementation of the Community Care & Health Act (2002) for local authorities, NHS and voluntary sector service providers.
- Draft Guidance Document NHS Carers Information Strategies: August 2004
A tool for NHS boards to understand the new requirements, and act on them, within the given timescale. It outlines purpose, context, format, content, and minimum requirements for local strategies, and seeks examples of existing good practice in providing carer information and support in NHS settings.

- Scottish Executive white paper (2003) 'Partnership in Care, on NHS Scotland. Outlines the proposal to develop a single Scottish Health Council, and Community Health Partnerships, which have a requirement to involve users and carers at all stages of consultation, implementation and monitoring.
- Care 21 report *The Future of Unpaid Care in Scotland and Building a Health Service Fit for the Future* (2005), recognises the value of carers as they support the independence and wellbeing of those they care for. Their contribution has been instrumental in preventing and delaying hospital admission and facilitating patient discharge from hospital.
- Scottish Executive Joint Futures promotion of a seamless service across the sectors, with the development of multi disciplinary teams, single shared assessment with specialist reports. Including carers assessment and self assessment documents..
- Scottish Executive Community Planning, involvement of 'Communities of Interest' in identifying needs and planning services.
- Social Inclusion.Policies now include carers as disadvantaged by their circumstances and role.

NHS Grampian Strategic Documents

- Grampian NHS Information Strategy for patients and the public February 2004 (draft) A strategic approach to for co-ordinating for co-ordinating management of health information for patients and the public.
- NHS Grampian 'Information for Carers' June 2004 (draft) A discussion document to develop a strategic plan to develop systems and procedures to identify carers and ensure that they have the information that they need, when they are in contact with NHS services..
- 'Integrated Healthcare System in Grampian' consultation paper August2004 Outlines the introduction of Community Health Partnerships, and potential ways forward in public involvement.
- Ladder of support and intervention Feb 2004 Outlines a hierarchical structure of involvement from 'Information to Decision making' based on Trevor Jones Model in 'Leadership in the NHS.'
- NHS Grampian Health Plan 2004/5 overview of priority areas for healthcare services, health inequalities in the region, and plans for service provision.