

NHS Forth Valley

Carers Information Strategy

Draft for Consultation

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CONTENTS

1	INTRODUCTION	3
2	THE CONTEXT	6
3	NHS FORTH VALLEY CARER INFORMATION STRATEGY	11
•	Appendix 1 – Action Plan	16
•	Appendix 2 – Carer Information Needs	26

1 INTRODUCTION

There are estimated to be 666,522 Carers in Scotland, 16% of the population. We are witnessing a steady annual 4.5% increase in Carer numbers, and increases in the amount and intensity of care provided. At present Carers in Scotland are estimated to save the public purse £5 billion per annum by providing unpaid care to friends and family members. It is clear that if this care were to be withdrawn health and social care systems would collapse. However, if Carers stop being able to provide care because of their own health problems, the pressure on these systems is significantly increased. We know that Carers have an increased likelihood of developing long-term health problems, often as a result of their caring role.

Recent findings published by Office for National Statistics offer worrying evidence of the detrimental impact of caring on the health of Carers.

- 39% of Carers say 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 amounts to an estimated 91,000 Carers in Scotland.

The NHS has an important role to play in supporting Carers.

Whilst this Strategy is for the NHS Forth Valley it is being developed in conjunction with our Local Authority Partners who have the statutory responsibility to carry out the Carers Assessments.

Carers will only be adequately supported and informed if positive and active partnerships between Carers, Local Authorities and the NHS are formed and sustained. Only in these circumstances will the best and appropriate information be available upon which assessment and service developments can be based.

Since the legislation that formalised Community Care was introduced in 1993, there has been a steadily increasing awareness of the contribution that informal / unpaid Carers make in supporting people at home. This contribution is increasingly important as the percentage of the population in Scotland that is older and dependent continues to increase.

Following devolution in 1996, the Scottish Executive required each Local Authority to prepare a Carers Strategy for their area. As the Joint Future initiative (formalising partnerships between the NHS and Local Authorities) gained momentum, the importance of including Carers in the planning and delivery of services was reinforced.

A major development has been the introduction of adult and young Carers entitlement to an assessment of their ability to care (Carers Assessment) independent of any assessment of the person for whom they care. This has been enshrined in legislation as part of the Community Care and Health (Scotland) Act 2002 which was implemented from 1 September 2002.

The Scottish Executive issued full Guidance on the legislation in March 2003.

The Act also provides for Scottish Ministers to require NHS Boards to prepare and submit to them a “NHS Carers Information Strategy”. This will set out how the Board will inform Carers who appear to them to be “substantial and regular” of their potential right to assessment under Section 12AA of the 1968 Act or Section 24 of the 1995 Act. Scottish Ministers may specify the date for submitting the Strategy, the form and extent of the Strategy, and the consultation that the Board must undertake in preparing it. NHS Boards must provide a copy of their Carer Information Strategy to any person who requests it.

The NHS Carers Information Strategy Working Group recommended that NHS CIS should be expanded to encompass the identification and provision of information to all Carers that NHS staff come across in their day to day duties. This would create a more consistent and strengthened approach to informing and empowering Carers.

2 THE CONTEXT

2.1 Who are Carers?

A Carer is someone who, unpaid, provides help and support to a relative, friend or neighbour who could not manage without that help due to frailty, long-term illness or disability.

Many Carers do not see themselves as Carers but primarily 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 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 impacts not only on individual Carers but also on whole family units.

2.2 The Role of Carers in Health and Social Care

Carers are a vital and central part of the whole Health and Community Care system. Carers are often the main providers of care to the person for whom they care. The drive towards delivering person-centred services that support people in their own home depends heavily at present on the contribution made by unpaid Carers.

Demographic change will mean a significant growth in the number of older people wanting to be looked after at home. Already many Carers are older people themselves looking after partners, husbands or wives. The contribution made by Carers will certainly continue to be vital and is likely to be increasingly valuable as Local Authorities, the NHS and other agencies strive to improve service provision.

While the numbers of people needing care are set to rise, social trends seem likely to reduce the number of potential Carers. Families have become less stable, smaller and more fragmented. Extended family networks, which may support a person with care needs, are becoming less common. This reinforces the need to support those Carers who want to take on caring responsibilities to family members and friends.

Carers must be valued and supported in their caring role.

2.3 Impact of Caring on Carers Own Health

Carers have a right to have their own health and social care needs met. There is sufficient evidence to indicate that caring has an impact on the health of Carers. For example in one study 51% of Carers had suffered a physical injury such as a strained back since they began to care and 52% had been treated for stress-related illness since becoming a Carer. [1] Another study revealed further evidence of the effects of caring on Carers' mental health. Of 93 Carers interviewed, 32% felt their health was affected by caring, 63% reported stress and 47% depression. [2]

Many Carers cope well with their caring responsibilities and require little or no support. But Carers' needs change and it is vital that Carers are identified early on in their caring role and provided with appropriate information on the sources of advice and help available to them. Early identification, information and support are critical. Too many Carers are not aware that support is available until they reach crisis point, a point at which their own physical and mental health is already often damaged.

Footnote 1 Source – Henwood, M (1998), Ignored and Invisible? Carers Experiences of the NHS (Carers National Association).

Footnote 2 Source – Liston R, Mann L, & Bannerjee – (1995) Stress in Informal Carers of Hospitalised Elderly Patient (Journal of the Royal College of Physicians).

2.4 Local Carer Strategies (covering each Council area)

The Scottish Executive's *Strategy for Carers in Scotland (November 1999)* provided a national framework for improving the support available to Carers. Central to the Strategy is the development of quality, flexible services to support Carers and to improve, both at a national and local level, the provision of information to Carers. Another aim of the Strategy is to give a new impetus to the way that statutory agencies work with Carers and involve Carers in care management and service planning decisions.

The Strategy has helped to deliver change. The creation of local Carer strategies, led by local authorities, and the creation of local Carer support structures have meant that the skills, expertise and knowledge of Carers is now being valued more at both a care management level and in terms of strategic planning of services.

One of the most pressing challenges is to ensure that supporting Carers becomes an integral part of the way that statutory agencies work. Carers are now **key partners** in the provision of care. The fundamental principle of Carers as key partners arose out of the development of the Carers' provisions contained in the Community Care and Health (Scotland) Act 2002. This development in the status of Carers is aimed at creating a fundamental shift in the way that statutory agencies work with Carers. Carers should not be regarded as a distinct client group needing support, but should be regarded as key service providers who need resources to help them deliver their contribution to the overall package of care.

In addition to the Carers Strategy key health and social care policies recognise and support the important role played by Carers. They include:

- Joint Working between Local Authorities, the NHS and the Voluntary and Private Sectors under the Scottish Executive's Joint Future Agenda.

- The Scottish Executive's Health White Paper - Partnership for Care
- Fair for All – NHS Scotland
- NHS Patient and Public Involvement Initiatives
- The Development of Community Health Partnerships
- Community Planning
- The Mental Health Treatment (Scotland) Act 2003
- The Executive's Development of New Hospital Discharge Protocols
- Integrated Children's Social Care Services
- Development of Home Care Services
- Implementation of the 'Same as you' – The Scottish Executive's Review of Social Care Services for People with Learning Disabilities
- Free Personal and Nursing Care
- Improved Access to Independent Advocacy
- The Scottish Executive Introduction of National Care Standards for Care Homes
- The Introduction of Direct Payments for Parents of Children with Disabilities (from June 2003)
- Adults With Incapacity (Scotland) Act 2000
- The Scottish Executive's Implementation of the Beattie Committee Report

2.5 NHS Role in Supporting Carers

Traditionally the lead for supporting Carers has been taken by local authority social work departments. As joint working across agency boundaries is being driven forward through mechanisms such as Community Planning and the development of Community Health Partnerships the NHS will have an increasing role in supporting Carers. Many health and social care services will be provided locally by a wide range of skilled staff working together as a team with other professions and agencies. This multi-disciplinary and multi partner approach is essential for the provision of local, integrated and improved services to support service users and their Carers. It is vital that Carers are embraced within these partnerships not just at a care management level but also at a strategic level in terms of service planning and design.

The NHS has a vital role to play in identifying Carers, offering them information and referring them on to sources of advice and support. It also has an important role to play in ensuring that Carers own health needs are proactively addressed.

Information is key to improving the health and well being of Carers. Information enables Carers to make early and informed choices about seeking practical and financial support. It helps Carers access support before they reach crisis point. It helps to tackle inequality and social exclusion for many 'hidden' Carers who are not aware that help and support is available.

In developing and implementing the NHS Forth Valley Carers Information Strategy, all involved must ensure that all Carers are included. Young Carers, those with mental health problems, Carers from ethnic minorities and other Minority Groups must have the same access to information, support and services as the wider Carer population.

3 NHS FORTH VALLEY CARER INFORMATION STRATEGY

3.1 Introduction

To ensure that the Carers Information Strategy is consistent across Forth Valley and throughout all parts of the NHS, a Reference Group has been established to oversee the development of the Carers Information Strategy. This has representatives from all 3 Councils, all parts of the NHS Forth Valley, Carers Organisations and Carers themselves. This Group will support the development of the Carers Information Strategy by the NHS Forth Valley. Consultation on the Strategy will take place with a much wider Group of interested parties throughout all 3 Council areas as progress is made.

Once the Strategy has been developed and is ready to be agreed by the Carer Forums in each Council area and the Statutory Agencies themselves, a decision will be taken on the kind of Forth Valley wide Group that will be needed to ensure implementation across Forth Valley. This will be part of the Consultation process.

The development of Strategies is often seen as an administrative or planning process. As the work on the Carers Information Strategy commenced the necessary operating managers and front line staff have not only been informed but are involved in the process directly. Membership of the Local Council area Carer Forums and Partnership Groups as well as the Reference Group will need to be reviewed to ensure that those involved directly in the provision of services are properly represented.

3.2 Our aim is to:

- Recognise and treat Carers as Key Partners in the provision of care.
- Work in partnership with Carers, local authorities, the voluntary sector and others to provide information to Carers as early as possible within the care journey.
- Provide information in a range of formats or languages enabling Carers to access information irrespective of their age, disability, ethnicity, gender religion / faith, sexual orientation or other specific needs.
- Inform Carers of their potential right to a Carers' assessment under the Community Care and Health (Scotland) Act 2002 and to direct Carers on to sources of information and practical support.
- Promote Carer awareness amongst all levels of NHS staff whether employed by or contracted to the NHS.

3.3 Outcomes for Carers

The outcome for Carers of our strategy will be that:

- Carers are identified early at first point of contact.
- Carers are informed of their potential right to an assessment of their support needs as Carer under Community Care and Health (Scotland) Act 2003.
- Carers are provided with all appropriate information.
- Carers are well informed of the process and procedures of hospital admission and discharge and are fully involved in the decisions taken at these key stages.
- Carers are equipped and supported to carryout effective caring.

3.4 Partnerships with Carers in Forth Valley

NHS Forth Valley is co-terminus with 3 Local Authorities. These are Clackmannanshire, Falkirk and Stirling. Each Council area has developed its

own structure for working in Partnership with Carers. Following the Scottish Executive's National Carers Strategy each Council was required to lead on the development of a local Carers Strategy and to consult with Carers and other interested Partners on the allocation of the funding that the Scottish Executive provided for Carers Support Services. In the years that have followed the following structures have been established in the Forth Valley area.

3.4.1 Clackmannanshire

Clackmannanshire is the smallest Council in Scotland and to maximise efficiency in these circumstances has created a "Strategy into Action Group" which brings together the Statutory Services, the Voluntary Sector and Carers in one Group. This meets regularly and the Carers Strategy, funding for Carers services and now the NHS Carers Information Strategy will be part of this Groups agenda.

3.4.2 Falkirk

Falkirk Council initiated a Carers Consultative Forum. This is now chaired by a Carer and attended by Statutory Organisations, the Voluntary Sector and individual Carers. An Annual Carers Conference takes place funded mainly by the Council and NHS in Forth Valley. The Consultative Forum agrees the Carers Strategy, the funding of Carers services and will now be party to the development of the NHS Carers Information Strategy.

3.4.3 Stirling

Following a survey and action research carried out by the Community Care Forum in Stirling, a Stirling Partnership for Carers has been established which also has representation from the Statutory Agencies, the Voluntary Sector and Carers. This Partnership will develop a Carers Strategy for Stirling, be a Forum for discussing the appropriate spending on Carers services and be involved in the development of a NHS Carers Information Strategy.

NHS Forth Valley is involved with all 3 Councils in the development of these Groups and in the work that they undertake. The introduction of the Forth Valley NHS Carers Strategy provides an opportunity to co-ordinate this work across the whole of Forth Valley area.

3.5 Links with Other Initiatives

The NHS Carers Information Strategy is being developed at a time of considerable change within the Health Service. The importance of listening to patients and Carers when planning and delivering services is being given more significance. Changes in the Partnership working arrangements between Health & Social Care have been steadily and consistently implemented in the last few years. In 2005 Community Health Partnerships will be established and take the joint working between Council and the NHS another step forward. There are a number of other initiatives alongside the development of CHPs. These are:

- Patient Focus / Public Involvement.
- Fair for All.
- Health Improvement.

The Carers Information Strategy has to ensure that all these initiatives are taken into account and that the aims and outcomes as listed on page 12 are achieved.

Carers Information Strategy – Development and Implementation

The aims of the Carers Information Strategy will only be achieved once it has been fully implemented. This will take a considerable period of time and an Action Plan is attached to this document detailing how the Strategy will be implemented and when. It is important for all Partners involved to recognise that agreeing the document is the beginning of a process that will bring a far

wider understanding of Carers and issues surrounding caring to all staff in all Statutory Agencies and Voluntary Sector Agencies thus enabling them to work with Carers as Key Partners in the provision of that care.

The Action Plan to achieve all this will be divided into different sections.

These sections are based on seven outcomes, with actions aiming to achieve the outcome.

A	NHS Forth Valley's structures and policies developed to be more Carer friendly and responsive.
B	Higher proportion of Carers Identified.
C	Information on NHS Services and services for Carers developed and available across Forth Valley, including Carers from Minority Ethnic Groups.
D	Identified Carers informed of their rights to an assessment of their own needs, including Carers from Minority Ethnic Groups, and Young Carers.
E	Carers are included as Partners in Care when: <ul style="list-style-type: none"> • Care plans are agreed. • Discharges are being made.
F	NHS Forth Valley staff are equipped and trained to identify Carers, access information for Carers and include them as Key Partners in Care.
G	Action Plan is implemented and monitored to ensure services are more Carer focussed.

Forth Valley NHS

Carers Information Strategy

An Action Plan

2005 to 2007

Ref.	Outcome	Indicator	Action	Lead	Timescale
A	NHS Forth Valley's structures and policies developed to be more Carer friendly and responsive.		<ul style="list-style-type: none"> Identify a lead Officer at General Manager or Senior Manager level in each CHP and the Acute Operating Division of Forth Valley NHS to promote Carer Identification and development of information and to be responsible for the implementation of this Action Plan. 	NHS Forth Valley Executive Group.	June 2005.
			<ul style="list-style-type: none"> Identify specific staff within Primary Care and Acute Care to promote Carer Identification and take responsibility for the provision of information to Carers. 	NHS Forth Valley Executive Group.	June 2005.

Ref.	Outcome	Indicator	Action	Lead	Timescale
			<ul style="list-style-type: none"> Develop proposals to identify and support Carers working within the NHS. 	NHS Forth Valley Executive Group.	March 2006.
			<ul style="list-style-type: none"> Review and revise current internal Carer Friendly Employment Practice. 	Director of Human Resources.	March 2006
			<ul style="list-style-type: none"> Ensure NHS Forth Valley Carers Information Strategy is integrated with each Councils Carers Strategy. 	Tom Hammond.	Dec 2005
			<ul style="list-style-type: none"> Ensure Carers Action Plan points are fully integrated with requirements of Race Relations Act, Fair for All etc. 	Tom Hammond.	Dec 2005
B	Higher proportion of Carers identified (including Young		<ul style="list-style-type: none"> Establish a Group and develop proposals for NHS 	Tom Hammond.	March 2006

Ref.	Outcome	Indicator	Action	Lead	Timescale
	Carers).		staff to identify previously unknown or hidden Carers.		
C	Information on NHS Services and Services for Carers developed and available across Forth Valley, including Carers from Minority Ethnic Groups and Young Carers and Carers of people with Mental Health problems.		<ul style="list-style-type: none"> Establish Council based Groups to review existing information available from NHS, Council and Voluntary Sector and identify gaps. 	Clacks, Falkirk, Stirling Councils. (TH NHS)	Sept 2005
			<ul style="list-style-type: none"> Develop information material for gaps identified in review. 	Clacks, Falkirk, Stirling Councils. (TH NHS)	March 2006
			<ul style="list-style-type: none"> Agree structure and process for disseminating information on Forth Valley 	Clacks, Falkirk, Stirling	June 2006

Ref.	Outcome	Indicator	Action	Lead	Timescale
			wide basis and for keeping it up to date. (See Appendix 2)	Councils. (TH NHS)	
			<ul style="list-style-type: none"> Establish Group to develop condition specific information (approach 3 appendix 2). 	Tom Hammond	Sept 2005
D	Identified Carers informed of their rights to an assessment of their ability to continue caring including Carers from Minority Ethnic Groups, Young Carers and Carers of people with Mental Health problems.		<ul style="list-style-type: none"> Ensure systems are in place to refer Carers on to sources of advice and support once identified and advised of their right to an assessment. 	CHP's / Council. Sue Dow / Brian Kerr, Falkirk. Kathy O'Neill / Deirdre Cilliers, Clacks. Eddie MacDonald / Irene	Dec 2005

Ref.	Outcome	Indicator	Action	Lead	Timescale
				Cavanagh, Stirling.	
			<ul style="list-style-type: none"> Develop proposals for NHS staff to ensure that Carers are referred to appropriate support services are made aware of their potential right to an assessment. 	CHP's / Council. Sue Dow / Brian Kerr, Falkirk. Kathy O'Neill / Deirdre Cilliers, Clacks. Eddie MacDonald / Irene Cavanagh.	Dec 2005
E	Carers are included as Partners in Care when: <ul style="list-style-type: none"> Care Plans are agreed. Discharges are being made. 		<ul style="list-style-type: none"> Review current Hospital discharge protocols to ensure that the issues concerning Carer 	Tom Whyte / Tom Hammond.	Dec 2005

Ref.	Outcome	Indicator	Action	Lead	Timescale
	<ul style="list-style-type: none"> Carers are equipped to carry out caring tasks. 		<p>identification, the provision of information to Carers, Carer referral on to source of advice and support and advising Carers of their right to an assessment is integrated into discharge procedures.</p>		
			<ul style="list-style-type: none"> Develop proposals for the development and provision of joint training for Carers aimed directly at supporting them in their caring role. 	Tom Whyte.	March 2006
			<ul style="list-style-type: none"> Ensure that NHS staff involved in the development and delivery of Hospital discharge protocols include the Carer as a key Partner 	Tom Whyte.	Dec 2005

Ref.	Outcome	Indicator	Action	Lead	Timescale
			in the provision of care.		
F	NHS Forth Valley staff are fully equipped and trained to identify Carers of all ages, access information for Carers and include them as Key Partners in Care.		<ul style="list-style-type: none"> Develop Education programme for ensuring that Carer Identification, the provision of information to Carers, the right of Carers to an assessment and Carers as a Key Partner in the provision of care are embedded in existing training programmes and any new ones under development. 	Morag MacKellar / Lesley Holdsworth.	March 2006
			<ul style="list-style-type: none"> Develop specific staff awareness training on culturally sensitive issues for Carers from Minority Ethnic Communities. 	Helena Buckley.	March 2006

Ref.	Outcome	Indicator	Action	Lead	Timescale
G	Action Plan is implemented and monitored to ensure services are more Carer focussed.		<ul style="list-style-type: none"> Identify joint performance indicators and outcomes for Carers (with Carers). 	Tom Hammond / David Whipps / Councils.	Dec 2005
			<ul style="list-style-type: none"> Provide baseline information against which quality improvements can be measured. 		Dec 2005
			<ul style="list-style-type: none"> Develop arrangements to monitor and evaluate implementation of the Carers Information Strategy. 		Dec 2005
			<ul style="list-style-type: none"> Ensure monitoring arrangements are consistent with requirement to account to the Scottish Executive within Performance Assessment Framework, 		Dec 2005

Ref.	Outcome	Indicator	Action	Lead	Timescale
			<p>Joint Health Improvement Plans, Patient Focus / Public Involvement, Local Health Plans etc.</p>		
			<ul style="list-style-type: none"> • Ensure that affective monitoring arrangements are in place to establish accessibility to information for Carers from Minority Ethnic Groups in line with the requirements of the Race Relation (Amendment) Act 2000 and the Boards Race Equality Schemes. 		Dec 2005

Appendix 2 – Carer Information Needs

Key Questions

- *Where do Carers go for information?*
- *Who do they see?*
- *Where else might they be sent?*
- *What are the barriers?*

- *What information do Carers want?*
- *What do they get?*
- *Where are the gaps?*
- *What do staff need in order to meet Carers information needs better*

Lack of Awareness

- *Carers may not recognise themselves as Carers*
- *Many Carers are reluctant to admit that they need help and to ask for help*
- *Carers are not necessarily aware of their own needs and the importance of their contribution*
- *Staff are not necessarily Carer aware*

Lack of Accessible Information

- *Carers often do not know where to start*
- *Carers do not know what questions to ask*
- *There is often too much information and too much inappropriate information*
- *Carers find it difficult to pick their way through lots of information*

In order to deliver the right information at the right time and in the right way a three approaches are needed.

Approach 1

Forth Valley wide information	Purpose
<ul style="list-style-type: none">• <i>Who is a Carer?</i>• <i>Carers rights</i>• <i>Where can Carers get support?</i>	<ul style="list-style-type: none">• <i>Identify hidden Carers</i>• <i>Help people identify themselves as Carers</i>• <i>Signpost to assessment and support services where appropriate</i>

Approach 2

Local Council area based Information	Purpose
<ul style="list-style-type: none">• <i>Local Community Care Services</i>• <i>Who to contact</i>• <i>Range of support and advice available to Carers in area</i>	<ul style="list-style-type: none">• <i>Enable cares to access support within local community</i>• <i>Provide staff with source of up to date local information for Carers</i>

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- Approach 3

Specific Information	Purpose
<ul style="list-style-type: none">• <i>Medical conditions</i>• <i>Medication</i>• <i>Specialist support groups</i>• <i>Individual care plan</i>	<ul style="list-style-type: none">• <i>Enable cares to access specific advice and information to help them care for an individual</i>• <i>Enable Carers to get support and self-help from people in similar situations</i>