



International signage for supporting carers

# Carer Information Strategy

2006/07 ~ 2009/10

October 2006

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**Thanks** – Bill Mason, Shetland Health Board, Carers Scotland

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## Executive Summary

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

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

The Scottish Executive has issued guidance on the production of Carer Information Strategies for the NHS. The Service has now produced this strategy for national guidance and local implementation alongside the overarching work of territorial Health Boards and Local Authorities.

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

The strategy highlights the need for early identification of carers. Key posts are identified within the Service with responsibility for leading and also for those in direct carer contact.

Carer awareness training for staff and managers will be implemented and further advice/ information links created.

This Carer Information Strategy complements and should be read alongside the Service Patient Focus and Public Involvement and Equality & Diversity strategies, as well as the work of the Reducing Health Inequalities Board.

It is recognised that the Service can not deliver the needs of carers on its own and will require to work in partnership with - Carers Association Scotland, territorial Health Boards and local authorities charged with making this strategy become a reality.

The Strategy covers all arms of the Service and in particular those that directly engage with patients and their carers – Accident and Emergency Service, Patient Transport Service and our Control Centres.

Finally, this strategy has not only been endorsed by the Carers Association Scotland, but perhaps more importantly, we have jointly agreed to a programme of development work over coming months and years that realises the crucial role of the Service at the beginning and end of the patient's NHS journey and the exceptional role played by unpaid and "non-professional" carers throughout.

## 1. Introduction

Scottish Ministers now require all NHS Boards by 31<sup>st</sup> October to prepare and submit to them for approval a “Carer Information Strategy”.

This is our first carers information strategy and it will enable us to:

- Help meet the statutory duty under the terms of the Community Care and Health (Scotland) Act 2002 to inform carers of their potential right to an assessment of need; and
- Meet the requirement of the Patient Focus Public Involvement (PFPI) initiative to have a strategy that meets the information needs of patients, relatives and carers.
- Better engage with and understand the needs of carers as we develop new clinical treatments, treat and leave and managed clinical networks

In delivering this strategy and its action plan; it is reinforced that we will require to work in partnership with territorial Health Board and Local Authorities, as well as those agencies that already provide advice and support.

## 2. Objectives

1. Carers are identified at an early stage and at any point of contact with the Service and provided with the information and advice they need.
2. The specific information needs of young carers (aged under 16), of older carers and of carers from black and minority ethnic groups are met, or more likely, identified to other agencies.
3. Carers are supported in partnership with other agencies so that they can continue to perform their caring role for as much and as long as they are willing and able to do so.

## 3. Consultation

In addition to internal consultation, the strategy was circulated for comment in early draft form to a number of stakeholder groups and individuals. These included:

- Carers Association Scotland
- Capability Scotland
- Age Concern (Scotland)
- Diabetes UK (Scotland)
- State Hospital Carstairs
- Asthma Association Scotland
- Equality & Diversity Steering Group & Manager
- Disability Rights Commission Scotland
- PFPI (Patient Focus Public Involvement) Steering Group
- The Service Involving People Group
- Reducing Health Inequalities Project Board
- Lanarkshire Drugs Action Tea
- Staff Union Convenors

All comments received by early October 2006 have been considered in finalising the strategy. Further work on developing the strategy will be a continuous process and kept under review by the Reducing Health Inequality Project Board annually.

## 4. Context

The 2001 Census identified 480,000 carers in Scotland of a total population of 5,000,000 - approximately 12% of the adult population. Most are aged between 45 and 64. 62% are women and 7% are parent carers. Approximately 50% look after someone over 75. 49% combine caring and employment (either full or part-time). 26% are retired and a further 25% are not in paid employment. In Scotland 63% of carers (310,000 people) care for up to 19 hours a week; 12.5% of carers (60,000 people) care for 20-49 hours per week; and 24% of carers (115,000 people) care for over 50 hours per week.

16,000 young carers were identified under the age of 18 who are providing care at home. It is thought this figure could be higher, as it is unlikely that the census identified young carers who care for others as a result of drug/alcohol misuse in the family or those who care for parents with mental health problems. A recent survey in the Highlands, for example, found that 10% of secondary school children provide care at home to a relative.

The same census recorded a minority ethnic carer population of 6,800, but local data suggests a significant under-enumeration of minority ethnic carers. Language and concepts around unpaid care may not be well understood within minority communities. It may also be more difficult to identify carers because of these communities' relative dispersal, the under-development of community services/networks and a lack of engagement with mainstream services and service planners. Little is also known about carers from white minority communities such as Eastern Europeans and Italians as well as carers within Scottish gypsy traveller communities who are also likely to face barriers to identification and support.

### Demographic Trends

Scotland's population is becoming healthier and people are living longer healthier lives (apart from those with chronic ill health in the lowest socio-economic groups). Despite that and continued progress in health technology and treatment, the next 10-20 years will inevitably bring a sizeable increase in the numbers of older people requiring care at home and in the community. This will mean a rise in the overall number of unpaid carers and in the number of carers who are themselves elderly. Research by Carers UK estimates a 60% increase in the number of carers across the UK by 2037, resulting from an increasingly older population. The Care 21 Report: *The future of unpaid care in Scotland, Delivering for Health and Changing Lives*, the findings of the Executive's 21st Century Social Work Review, all acknowledge the increasing importance of unpaid care in the years to come as a means of supporting self care and self management of people with support needs.

### Information needs of carers

Service users and carers need information to:

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

The Service can help to provide this for its own services and increasingly signpost carers toward other more relevant agencies.

## 5. Policy Framework

### Nationally

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

- SEHD HDL (2006) 22, April 24 2006 - NHS Carer Information Strategies: Minimum requirements and guidance on implementation
- Adults with Incapacity (Scotland) Act 2000
- Carers (Recognition and Services) Act 1995
- Children (Scotland) Act 1995
- Community Care and Health (Scotland) Act 2002
- Fair For All, 2002
- Mental Health (Care & Treatment) (Scotland) Act 2003
- NHS & Community Care Act 1990
- Race Relations Amendment Act 2002
- Scotland's Health White Paper "Partnership for Care" 2003
- Strategy for Carers in Scotland 1999
- The Work & Families Act Scotland (coming into force April 2007)

### Locally

This strategy requires to be read in conjunction with other local partnership agreements and action plans designed to address local need with Local Authorities, Voluntary Groups and territorial Health Boards. As well as the Service, Race Equality Scheme, Disability Equality Scheme and strategies for PFPI and Equality & Diversity et al.

## 6. Definitions & Rights

**A carer** is generally defined as a person of any age who provides voluntary unpaid help and support to a relative, friend or neighbour who cannot manage to live without the carer's help due to frailty, illness, disability or addiction. In the Carers (Recognition and Services 1995 Scotland) Act the definition used applies to adults and young people who provide or intend to provide "a substantial amount of care on a regular basis" for people who require community care. This will also cover Service employees who are also carers in their private life. The support a carer provides may include moving and handling, help with feeding, personal hygiene and administering medication as well as providing emotional support, acting as an advocate or guardian for the cared for person and enabling the person with support needs to access leisure and recreation."

**Adult Carers** are recognised by the Scottish Executive as "**key partners** in providing care" with local authorities, the NHS and other support agencies. Although adult carers, who are the parents, do not have the same rights under the 1995 Scotland act, they will be given new rights in the Work & Families Act 2007.

**Young Carers** i.e. carers aged under 16, are recognised as a distinct group with specific needs. We are committed to the requirement to ensure that a child does not have a level of caring responsibilities that may undermine their ability to participate in education, leisure or social activities – although this aim can only be delivered in practice through partnership working with other agencies.

Carers have a **right to an assessment** to establish their “ability to provide or continue to provide care” for another person. Assessments for carers are an integral part of the Single Shared Assessment process and are available to anyone who provides “a substantial amount of care on a regular basis”. Again, this can only be delivered by other agencies, but we can provide access advice.

## 7. SE NHS Guiding Principles – August 2004

These are included as a useful way to identify the important principles and ways in which we can help:

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

This means that:

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

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

This means that:

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

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

This means that:

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

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

This means that:

- General information will be made available in formats and languages that are accessible to, for example, young carers, carers with learning disabilities or sensory impairment, older carers and carers from black and minority ethnic groups.

- Carers will be identified through the assessment process and specific information relevant to their own circumstances will be made available and accessible to them as appropriate.
- Carers will be advised of NHS and Council complaints procedures.
- Staff will understand the needs of carers and having the knowledge to meet carers' needs for appropriate information and advice.

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

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

This means that:

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

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

This means that:

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

**8. Staff at all levels of NHS and in the local Council will work in partnership with a wide range of stakeholders to promote the needs of carers.**

This means:

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

## 8. Roles and Responsibilities

### Lead Officers

The Lead Director for the Scottish Ambulance Service with responsibility for the effective development and monitoring of the Carer Information Strategy is the Director of Human Resources & Clinical Development.

General Managers in each of the six territorial divisions of the Scottish Ambulance Service are responsible for the implementation of all Service policies and for the continuous integration with partner agencies. This function is reviewed as part of the annual accountability review.

### **Patient Focus and Public Involvement Initiative**

The national coordinating officer for the Patient Focus and Public Involvement Initiative is the General Manager North East Division, who chairs a national steering group. Local PFPI initiatives involve carers who take part in focus group activities on a range of topics and contribute to reviews of policies and procedures. We have and will continue to use our PFPI network to develop this strategy and to assess its impact.

### **Equality & Diversity Initiative**

The national coordinating officer for the E&D initiative is Ann Tobin who chairs a national steering group. Local initiatives may involve members from all Scottish communities and outcomes are designed to improve awareness and participation.

### **Training Managers**

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

### **Line Managers/Supervisors**

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

**Voluntary Sector Organisations** – the Service works in partnership, locally and nationally, with a number of organisations in the voluntary sector providing information on the services they provide and who to contact. These can, for example, in specific cases include:

- Diabetes UK
- Asthma Society
- Capability Scotland
- Red Cross
- Age Concern
- British Heart Foundation
- Citizens Advice Bureau (who provide, free at the point of contact, confidential advice)
- Community Drugs teams

### **Training For Carers**

The Service is able to offer training (sometimes a charge may be made to cover actual costs) in a number of specific areas to carers or coordinators:

- Moving & Assisting
- First Aid
- Administering medication
- Mental Health First Aid
- How to call for help

Carers can access funding via the Social Work service to cover reasonable travel and accommodation costs and course fees for specialist training courses.

### **For employees**

The Service has a number of policies covering flexible working arrangements and further advice is available from the Personnel team. This will be reviewed in light of the "Work & Families Bill" that gained Royal assent on 21<sup>st</sup> June 2006 and will come into effect in April 2007 enabling carers to better juggle work with their caring role.

### **For All Staff**

Carer awareness issues will be included in basic entry and induction programmes for all frontline staff / practitioners and will cover carers potential entitlement to an assessment, identification of carers (and especially those who are struggling to cope or who are not engaged with support agencies), and diversity /equality issues. This is being introduced into the Service in partnership with Carers Scotland.

It is the responsibility of all to share information for continuity of care purposes, protecting vulnerable people and those who are at risk, or in the public interest. Otherwise, the patient and or carer must agree for information to be shared with other agencies.

## **9. Quality Framework and Monitoring**

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

### **Information materials & consultation exercises**

Review by PFPI and E&D groups taking into account the following attributes:

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

### **Training**

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

### **Carers Complaints**

Issues arising from carers' complaints will be identified by the complaints administrator and reported to the Reducing Inequalities Project Board.

The lead Director is also responsible for preparing an annual progress report to the Scottish Executive and SAS Board.

## **10. Conclusion**

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 at Appendix 1 detailing many of the action targets. It is important for everyone involved to recognise that accepting the strategy is the beginning of a process that will bring a far wider understanding of carers and issues surrounding caring to all staff.

It is clear that carers are essential to the future of healthcare and to our own vision of reducing unnecessary hospital attendances and we must therefore do everything in our power to support and inform those who are prepared to do this vital work, unpaid and often without proper recognition.

**Shirley Rogers**  
**Director of Human Resources & Clinical Development**

**October 2006**

## Appendix 1 – Action Plan

Action	Rolling Timescale	Lead Person/ Group
Drafting & regular Review of this strategy & linked documents, particularly on introduction of new linked documents	At each quarterly meeting	Reducing Inequalities Board, W Mason
Internal & external Consultation, including partnership & PFPI stakeholders	Part of an ongoing programme	S Rogers, General Managers
Implementation of all guiding principles	Within life of strategy	General Managers and operational staff
Ensuring compatibility & compliance with Risk Management Standards	During 2006/07	P Gowans
Ensuring compatibility with Electronic Patient Care Form and Cab based terminals, Including development of new advice/guidance leaflets with Carers Association.	During 2007/08	R Lawrenson
Ensuring compatibility with Vulnerable children & adults, Research & Development, Ethics & Clinical Excellence Framework	Immediate and thereafter at each annual review	W Mason
Ensuring compatibility and compliance with Data Protection & Confidentiality	Immediate and thereafter at each annual review	R Johnston
Ensuring compatibility and compliance with Equality & Diversity policy	Immediate and thereafter at each annual review	A Tobin & all staff
Ensuring compatibility and compliance with PFPI policy	Immediate and thereafter at each annual review	N Barber and all GMs
Ensuring compatibility with Freedom of Information	Immediate and thereafter at each annual review	R Panton
Review written materials and corporate information and ensuring compatibility	Immediate and thereafter at each annual review	R Panton
Ensuring compatibility with Information Governance	Immediate and thereafter at each annual review	W Mason
Ensuring compatibility with training materials, developing new course content and implementation. In association with Carers Association Scotland.	During 2007/ 08	G Kelly & training team
Ensuring treat and refer/ clinical care pathways reflect requirements	Immediate and during life of project	D Scott, Clinical Effectiveness team
Clinical Governance & Board approvals	Immediate and at annual report	S Rogers
Posting to Samson	On approval	W Mason
Paper circulation to GMs and Heads of department	On approval	S Rogers
Frequent Caller identification implications for carers	During 2007/ 08	D Wemyss, Reducing Hospital Admissions
Operational Implementation & annual review	On approval and annually	P Moore & GM's
Complaints monitoring	Immediate	J Conlan
Draft annual progress report	At review date	W Mason
Integrating SAS policy/ activity with that of Local Authorities and Health Boards	Immediate and on-going	General Managers and local management teams
Developing with Carers Association appropriate ELearning materials	During 2007/ 08	J Whyte
Continuing to consider ways to work more closely with other agencies e.g. Carers Association to ensure we create integrated best practice for working with carers.	Continuing	All
Response Magazine article on carer involvement	Completed Oct 06	W Mason

**Appendix 2 – Patient/ Carer Advice Form**

**Scottish Ambulance Service**

**Patient & Carer Information Form** (only used for "see and treat" cases, where patient is not transported)

Patient's Name:	SAS Case No:	Crew ID:
Patient's Date of Birth:	Patient's CHI No (if known):	
Patient's Address:		

An Ambulance attended you at ..... (Time) on ..... (Date) because you experienced:

We have assessed your condition and, in accordance with our procedures, it is our judgement that you **do not** need to be transported to hospital, or any other care provider at this time. Our advice is that you (patient and or carer) should now do the following:

We have left you a copy of this form and our Patient Care Record, which provides further information about your clinical signs and what treatment (if any) was provided. Please send or take this form to your Doctor for his/ her information and to file with your Medical Records, as soon as is possible.

The information in these forms is not intended to provide a final diagnosis or complete care advice. We recommend that you always contact your own care practitioner after our visit.

**Important Information - if there is any change in your condition such as:**

1. Another worrying episode of your condition occurs
2. If you feel unwell or get worse in any way
3. If anyone else has any concerns about you
4. If you feel increasingly vulnerable or at risk from something or someone
5. If your care arrangements break down, or you find it difficult to care for yourself

You should immediately contact one of the following - Your Doctor or Practice Nurse, or NHS 24 on **0845 4 24 24 24** (out of hours); or if it is an emergency call **999**.

If you do not understand, or disagree with what is being done – please discuss your concerns with the ambulance team **before** they leave. You may also feel that the advice or presence of a friend, neighbour, relative or other carer, may be helpful and the crew may be able to help you contact someone.

To benefit your future health and wellbeing, this form and the care record **MAY** be shared with other appropriate Health or Social care providers, including NHS24 for the purposes of continuing care, health records or clinical audit, **UNLESS** you explicitly refuse by signing in the attached box. Our recommendation is that you **DO** allow information to be shared.

I do not wish my information to be shared:

Crew Information – give top copy to Patient / Carer along with a copy of PCR. Attach carbon copy to SAS PCR. To protect vulnerable people & public safety, patient agreement is not necessary for proportionate information sharing. This form is not to be used for non-approved "See & Treat" cases or as a substitute for patient refusal (which must be recorded elsewhere)!

## Appendix 3 – Collaborative opportunities with Carers Scotland

**CARERS** Scotland  
the voice of carers

Mr Bill Mason  
National Continuous Improvement Manager  
Scottish Ambulance Service  
National HQ  
Tipperlinn Road  
Edinburgh  
EH10 5UU

24<sup>th</sup> October 2006

Dear Bill,

### **Scottish Ambulance Service: Collaborative opportunities.**

It was good to meet with you on Friday. Pat and I found the meeting to be extremely positive and informative. It was particularly useful to have sense of the ambulance service as a whole and we are delighted that there are a number of areas where we can work together now and in the future.

We would like to confirm the following:

- We will be happy to contribute to your strategic management group and look forward to receiving a formal invitation. We would also be happy to consider representation on the local Stakeholder group in Lanarkshire.
- We will be pleased to contribute to the development of the electronic patient record. To assist in this we are happy to accept you offer to visit the control centre in Paisley and to spend time with an operational unit to better understand what happens at the first point of contact.
- We will be very pleased to develop jointly a range of information leaflets for carers to be available in your ambulances. Fiona Collie, our Policy & Parliamentary Affairs Manager, would take the lead on this. Her Email address is: [Fiona.collie@carerscotland.org](mailto:Fiona.collie@carerscotland.org)
- Fiona has attended the Involving People group with Shirley Rodgers, Director of HR and Clinical Development.
- When your strategy is agreed we would be delighted to meet with your training department to discuss the provision of carer awareness training. Jacqui Taylor would take the lead on this. Her Email address is [Jacqui.taylor@carerscotland.org](mailto:Jacqui.taylor@carerscotland.org)
- We will arrange for Margaret Smith, ACE Policy & Service Development Worker, to contact you regarding our ACE (Action for Carers in Employment) Stakeholder Group. You indicated that your Planning, Equality & Diversity Manager may be interested in attending. In the meantime we have asked Margaret to send you information on the work of the group and the date of the next meeting. Her E-mail address is [Margaret.smith@carerscotland.org](mailto:Margaret.smith@carerscotland.org)
- As agreed we will send the following publications:

- o information on 'Learning for Living', the on-line personal development course for carers.
  - o a copy of Michael Hirst's research - Hearts & Minds for information.
  - o an example of our newsletter with a 'pull-out' section. We would be happy for you to provide an insert on the ambulance service for a future edition.
- We would welcome the opportunity to be involved in any future research activities with Stirling University and yourselves.

Once again thank you for meeting with us. We look forward to working in partnership with you. In the meantime should you require any further information or clarification please do not hesitate to contact either myself or my colleagues.

Yours sincerely

Patrick J Begley  
Director

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