



The Princess Royal Trust  
for Carers

# Focus on Carers and the NHS – identifying and supporting hidden carers Good Practice Guide Executive Summary

Over 600,000 people in Scotland are unpaid carers. That means one in eight of us will care for someone else at some point in our life. Carers are crucially important to the person they look after, providing a range of assistance from advocacy and emotional support to personal care and practical help with every day matters. Many people in our communities rely on the care provided by carers. Our health and social care systems benefit greatly from their immense contribution.

Carers have a key part to play in supporting the care the NHS provides, and helping the NHS understand the needs of the person they care for. The critical role of carers as main care-providers must be recognised and acted upon at all levels in the NHS. Being a carer can also bring its own health costs. Many carers find their health suffers as a direct consequence of the physical or emotional strains of caring. To help protect their own health and well being carers need to know early on in their caring role that support is available. GPs and other primary care professionals are well placed to identify carers and alert them to sources of help and advice. The benefits of this have been proven by the innovative and pioneering work carried out by The Princess Royal Trust for Carers through its Focus on Carers initiative and its associated work with community pharmacists. The Executive is pleased to have been able to support the Trust in these projects.

This good practice guide contains

important messages for everyone involved in supporting carers. It will help inform the introduction of NHS Carer Information strategies, as required by the Community Care and Health (Scotland) Act 2002. The Scottish Executive will be providing advice to Health Boards on the implementation of these strategies. In the meantime, I very much welcome the proactive approach of those Health Boards who are already developing strategies in partnership with carers and local authorities.

Supporting carers is not an optional extra. Supporting carers is a must, if we are to enable them to go on supporting the most vulnerable people in our communities. We all have an important role to play in making that happen.

An extract from the Foreword to the Good Practice Guide by Trevor Jones, Chief Executive of the NHS in Scotland.

## CARERS AS KEY PARTNERS IN THE PROVISION OF CARE

The NHS Scotland's Health White Paper – Partnership for Care lays strong emphasis on partnership working *'Many people who come into contact with the service already rely on care given by an informal carer. These carers are crucially important to the person they look after but they can still find themselves marginalized by health service professionals. The vital role of carers as major care providers must be recognised at all levels in the NHS and staff must work closely with carers as partners in providing care.'*

The report of the Scottish Carers' Legislation Working Group 2001

highlights that

*'The majority of carers are likely to be known to the health service first – either because of the health of the person they care for, or the impact of caring on their own health. We believe strongly that improving the capacity of NHS Scotland to identify and refer carers on to other agencies is one of the most powerful ways of improving the lives of the large numbers of carers who currently get little or no support.'*

## Who is a carer?

A carer is someone who, without payment, provides help and support to a relative, friend, or neighbour, who could not manage to stay at home without their help due to age, sickness, addiction or disability.

Carers look after relatives and friends at home, often at great personal and financial cost. There are almost as many male carers as female, they can be of any age and background, and some combine a paid job with their caring role. However, a significant number do not consciously recognise themselves as carers. They see their role as that of husband, wife, daughter, son, relative or friend. They are often referred to as 'hidden carers' and are not clearly identified by statutory bodies and therefore do not receive the recognition or support they need.

The initial point of contact for many carers with statutory services is the health service, via their GP, community nurse or other member of the Primary Health Care Team (DOH 1999) and this is often precipitated by a crisis.

## SCOPE OF THE FOCUS ON CARERS AND THE NHS – GOOD PRACTICE GUIDE

There are many different organisations working with and supporting carers. The Focus on Carers and the NHS – Good Practice Guide can be used by a wide range of professionals. Although the case studies provide examples of the partnership work promoted by Carers Centres, the methodologies can be used in other partnership work across carers' services. GPs and primary health care teams have an important role in the identification of carers, as reflected in legislation (Community Care and Health (Scotland) Act 2002), and it is hoped that this guide can be a useful source of information for:

- staff in Carers Centres planning to work or already working with GPs and primary health care staff
- GPs and practice staff
- NHS and local authority community care staff
- pharmacists
- acute hospital staff especially those involved in the process of patient discharge
- staff in all carers services including Crossroads, Carers Scotland and Carers UK
- anyone with an interest in carers and carers' issues.

## HIGHLIGHTING THE SUCCESSES

To date, over 10,000 carers have been identified using a range of methodologies. But quantity is not everything, and a desire for the rapid expansion of this work is tempered by a concern that the quality of service is not weakened by stimulating demands

and expectations which are difficult to meet. It is vital that these methodologies are carried out with care, consideration and effective planning. Furthermore, if additional funds were made available, it would be possible to find and support an increasing number of carers using the methodologies outlined in the Good Practice Guide.

The Focus on Carers Initiative is endorsed by the British Medical Association (Scotland) and recognises that GPs and other primary health care workers are a key contact point for carers and hence a vital partner in the identification of carers throughout the country.

*'As a family doctor, I have always been impressed by the dedication shown by carers to vulnerable patients – but at the same time struck by the lack of provision for their needs through the statutory agencies. This is why I have been so pleased to be involved with the Focus on Carers Initiative.'*

Dr Brian Keighley BMA Scotland

## THE PRINCESS ROYAL TRUST – FOCUS ON CARERS INITIATIVE

Since its inception, The Princess Royal Trust for Carers has known of the critical gate-keeping role played by GPs and primary health care staff, and wanted to support the development of systems which would engage them in developing methodologies to identify and support carers.

In an effort to develop these methodologies effectively and to highlight the issue of hidden carers, the Princess Royal Trust for Carers Focus on Carers Initiative was launched in

Scotland by HRH The Princess Royal in November 1998.

The overall aim of the initiative was to establish partnerships between GPs, primary health care staff and local Princess Royal Trust Carers Centres, to help identify and provide support to carers. The desired outcomes were to:

- identify carers and provide them with information about their nearest Princess Royal Trust Carers Centre or outreach site
- ensure that carers' needs are assessed and appropriate action taken
- establish a clear agenda for action for local service providers
- provide a rigorous analysis of the numbers and needs of carers
- highlight the level of services required
- provide training and awareness-raising to participating practices through Carers Centres
- provide a more strategic approach to community care planning
- establish methods of working that can be replicated throughout the UK.

## IDENTIFYING HIDDEN CARERS WITHIN PRIMARY CARE SETTINGS

There are many ways of reaching carers who have contact with the various health professionals within a practice. Successful partnership approaches to identify and support hidden carers include the following methodologies:

### Mailshot Identification

This method identifies carers through the use of a letter and short questionnaire being sent directly from the GP to an agreed set of patients.

This may be a particular age group or those with particular illnesses or medical conditions. From experience of using this approach the return rate is on average 6% of the total patients contacted.

#### On-site identification

This method of working places staff within a health centre or practice setting for an agreed number of hours per day generally over a four to six week period. During that time they approach all patients entering the practice, or whilst they are waiting for their appointment, and ask if they are carers.

#### Using notice boards and general publicity material to raise awareness

A notice board and a range of publicity material can be used throughout the health setting for patients to take away or read, and is a permanent feature of a practice or health centre.

#### Direct awareness-raising

Staff can work with community-based health staff such as district nurses or health visitors in direct awareness-raising sessions. This provides health service staff with details of service provision and contact cards and letters to distribute to patients and/or their carers where appropriate.

#### Variations

- Develop the on-site model to work in a range of health settings such as local clinics, day care centres, waiting areas in pharmacies or acute hospitals with permission from the appropriate managers.

### CASE STUDY

#### Minority Ethnic Development Worker – Princess Royal Trust South Glasgow Carers Centre

This post, funded by Glasgow City Council through Carers Strategy Money, has effectively used direct publicity material to encourage carers from the local minority ethnic community to come forward for advice and support. The worker was involved in providing direct contact and support to carers in addition to providing culturally sensitive translated materials. This encouraged members of the local minority ethnic community

to approach Carers Centre staff for support. The worker has also collected translated materials to create a library for carers and professionals which complements the existing Carers Centre resource material.

The worker also raised the profile of minority ethnic carers by making presentations to local voluntary and statutory organisations, and by establishing work in venues such as the elderly daycare project based in Glasgow Central Mosque. In the first six months of this post the worker identified 240 carers, and 155 of those were as a direct result of the Focus on Carers Initiative.

*This case study illustrates the value of providing material appropriate to the particular group of carers you are aiming to identify.*

- Attend specialist clinics in the practice, such as those held for flu vaccinations or over-75 health check.
- Hold 'carers' surgeries' on a regular basis for two hours two days per week, providing information and advice on-site in the surgery. This enables GPs to make quick referrals and give carers immediate contact with the carers' support worker.

#### Positive feedback

In one area where the on-site method was undertaken twice in one year the practice manager reported, '*the second time the Carers Centre staff came here we had a number of people turn up in the practice only to see them not the GP. Patients had spread the word to friends and neighbours that they were in the practice.*' A GP commented to

his practice manager that a number of patients had thanked him for providing the service.

### PHARMACY INITIATIVE

#### Overview

600,000 people a day use the services of the 1150 pharmacies in Scotland. Of those collecting prescription medication, it is estimated that 80% will be for repeat prescriptions. It is also likely that a substantial number of these repeat prescriptions will be collected either for or by carers, thus placing community pharmacists in a pivotal position to establish contact with carers. In January 2001 the Royal Pharmaceutical Society in Scotland hosted an event at the Palace of Holyroodhouse, and agreed to work in

## CASE STUDY

### PRT Moray Carers Centre

The centre manager contacted the local pharmacist in Forres, who was very enthusiastic and undertook to brief the pharmacy staff on the implementation of the initiative. The cards and letters were delivered to the pharmacy and the initiative got underway.

The manager contacted the pharmacy at regular intervals to update the staff on the outcomes and numbers of carers identified.

To build on this enthusiasm, the

centre manager arranged with the press for articles to appear in the local newspapers promoting the initiative, including photographs of the pharmacy. This not only publicised the search for hidden carers – raising awareness in the newspapers' readership – but also provided an excellent incentive when introducing the idea to other pharmacists.

The outcomes were very successful for this approach. A total of 8,340 cards were handed out by the pharmacy, and produced 100 responses from carers, which is a

1.2% return.

Approximately two thirds of those carers identified asked to be included on the centre's mailing list, whilst the remainder requested help in areas such as benefit checks and information about the law regarding disability, and how to access additional services.

Although surprised at the level of response, the centre had made sure they would be prepared, by having the initial information and resource packs ready to be sent to the carers on request.

partnership with the Trust to forge a strategic alliance aimed at stimulating the active involvement of pharmacists in finding hidden carers who could be helped by local carers' services.

### Methodology

This initiative aims to inform carers of the services that are available from their local Princess Royal Trust Carers Centre, by means of a letter and a reply card put into each prescription bag collected by the customer, over a time-limited period.

### Positive feedback

*'It promotes a professional image of the pharmacy service and provides a holistic care service to the patients and carers. I am very satisfied with the*

*outcomes and feel that the level of newly identified carers more than paid back the small effort it took'.*

Pharmacist in rural area

## HOME FROM HOSPITAL INITIATIVE

### Overview

Recent studies carried out for the Department of Health highlighted the need for open communication and information-sharing with patients, during the hospital admission and discharge process. An integral part of this is the recognition that carers are key partners, who should be actively consulted by health practitioners in the planning and delivery of care for a patient, as reflected in the NHS Scotland White Paper (Scottish

Executive 2003).

The Home from Hospital Initiative is based on a recognition that the point of discharge from hospital is an important opportunity to identify and support carers at the start or resumption of their caring responsibilities.

### Positive feedback

This working partnership has helped to highlight and to validate the carers' role as 'partners in the provision of care' and was publicly acknowledged at the Lothian NHS Symposium September 2002 by Brian Cavanagh, Chairperson of NHS Lothian Unified Board:

*'NHS staff need to be much more attuned to carers as partners – the time has come for carers to knock on the door of NHS Lothian. They will get a welcome'.*

Further background information and details of each of the methodologies are contained in the 'Focus on Carers and the NHS: Identifying and Supporting Hidden Carers - Good Practice Guide'. This publication is available from The Princess Royal Trust for Carers Offices listed below, or from the Trust's website at [www.carers.org](http://www.carers.org)



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