



The Princess Royal Trust  
*for Carers*

# Focus on Carers and the NHS – identifying and supporting hidden carers

## Good Practice Guide





# Foreword



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.

Changes in population age, family structures and employment are likely to increase the future number of carers, and the pattern of care they provide. It is more important than ever that we recognise and work with carers as key partners in the provision of care. The carers' measures contained in the Community Care and Health (Scotland) Act 2002 reflect the need for partnership across health and social care. Scotland's Health White Paper "Partnership for Care" also sends clear messages to the NHS about the importance of supporting carers.

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.

As well as bringing real benefits to many carers, including many young carers, the Trust's work has helped to raise carer awareness within the NHS. The NHS is starting to embrace the carers' agenda. In some Health Boards progress is significant but existing good practice needs to be adopted more universally. The Executive is seeking to make that happen through clinical standards, patient and public involvement and by working closely with GPs and other health practitioners. That work will be undertaken within the wider organisational and cultural changes now underway across health and social care. Demarcation barriers across organisations and between professionals are now being dismantled and replaced by more effective partnership working and structures where resources can be more easily shared and front line staff increasingly empowered. These changes are already creating quicker decision making, more joined-up services and improved support and involvement for patients, service users and carers.

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.

Trevor Jones  
Chief Executive of the NHS in Scotland



# Acknowledgements

This Good Practice Guide reflects the work undertaken in partnership with a range of organisations in the Statutory and Voluntary Sector and the commitment of our colleagues in Carers Centres to pioneer new approaches to finding and supporting hidden carers.

We are extremely grateful to those Carers Centres whose direct experiences have provided the basis for this publication. They are:

- PRTC South Glasgow Carers Centre
- PRTC Dumfries and Galloway Carers Centre
- PRTC Fife Carers Centre
- PRTC Borders Carers Centre
- PRTC Dundee Carers Centre
- PRTC Moray Carers Centre
- PRTC East Ayrshire Carers Centre
- PRTC Vocal Carers Centre

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From its inception this initiative has been supported by the Steering Groups for both the Focus on Carers and Pharmacy Initiatives. The commitment and personal involvement of members of these groups has been invaluable. Generous support has been provided by the Scottish Executive with funds which enabled the Trust to extend the work with GPs and their colleagues and provided the initial funding to pioneer work with pharmacies in Scotland.

The original development of this initiative was made possible through generous financial support from Prudential plc and their direct involvement on the Task Force.

The Trust is indebted to Greater Glasgow Primary Care NHS Trust for the secondment of Shona MacInnes for two years and for the invaluable role which Shona had in supporting the development of this initiative.

Finally we would wish to acknowledge and thank Jo Clifton for her work in editing the Good Practice Guide and to all staff within The Princess Royal Trust for Carers who have assisted with this work.

## **Colin Williams OBE**

Director Scotland

The Princess Royal Trust for Carers



# Contents

Pages 04–07	<b>Introduction</b> Who is this Guide for? Why produce a Good Practice Guide? Background Information <ul style="list-style-type: none"><li>• Who is a carer?</li><li>• Researching the need</li><li>• Driving the initiative</li></ul> GP and Primary Health Care Initiative Pharmacy Initiative Home from Hospital Initiative Highlighting the successes	Pages 18–20	<b>Pharmacy Initiative</b> Overview Checklist for initiative Methodology <ul style="list-style-type: none"><li>• Preparing the ground</li><li>• Keeping records</li></ul>
Pages 08–10	<b>Overall Guidance to Planning the Initiative</b> Identify the resources <ul style="list-style-type: none"><li>• Material costs</li><li>• Personnel</li></ul> Referrals to other agencies Support from The Princess Royal Trust Checklist 1	Pages 21–23	<b>Home from Hospital Initiative</b> Overview <ul style="list-style-type: none"><li>• Development of the initiative</li></ul> PRTC East Ayrshire Carers Centre <ul style="list-style-type: none"><li>• Benefits to carers and patients</li><li>• Benefits to hospital staff</li><li>• Tips from this initiative</li></ul> PRTC Vocal Carers Centre
Pages 11–17	<b>GP and Primary Care Initiative</b> Checklist 2 Overview Preparing your case Making the approach Presenting the case <ul style="list-style-type: none"><li>• Direct contact with the GPs</li><li>• Working with the practice manager</li><li>• Making the agreement</li></ul> Methodologies <ul style="list-style-type: none"><li>• What will work best for you and the local GP practice</li><li>• Mailshot identification</li><li>• On-site identification</li><li>• Using noticeboards and general publicity material to raise awareness</li><li>• Direct awareness-raising</li></ul>	Pages 24–26	<b>Monitoring and Evaluation</b> Overview Data collection and collation Evaluation Using the information Measuring outcomes against input
		Pages 27–28	<b>Further Reading</b>
		Pages 29–38	<b>Appendices</b> <ol style="list-style-type: none"><li>1. The Data Protection Act 1998</li><li>2. Hidden carers flowchart</li><li>3. Mailshot Guidelines</li><li>4. Draft letter from GPs to accompany questionnaire</li><li>5. Mailshot questionnaire</li><li>6. Questionnaire for on-site contact</li><li>7. Questionnaire analysis</li><li>8. Presentation slides about the Primary Care Initiative</li></ol>

# Introduction

## WHO IS THIS GUIDE FOR?

There are many different organisations working with and supporting carers. This guide can be used by a wide range of professionals in different ways. Whilst the case studies provide examples of the partnership work promoted by Carers Centres, the methodologies given can be used in other partnership work across carers' services, as well as within health and social work services.

GPs and primary health care teams have an important part to play in the identification of carers, as reflected in legislation (Community Care and Health (Scotland) Act 2002). 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.

## WHY PRODUCE A GOOD PRACTICE GUIDE?

Within The Princess Royal Trust for Carers those centres involved in joint work with health professionals throughout Scotland indicate that they benefit considerably from sharing experiences of partnership working with each other. Checking out what works and what doesn't – and more importantly why – means a reduction in the amount of trial and error when starting something new, or developing existing work.

Although methods have been devised and adapted to suit local Carers Centres, there are common themes that can be used successfully by existing healthcare staff, or staff from other statutory or voluntary agencies.

Many centre managers expressed the view that positive experiences promote positive relationships and that this is an important aspect of sharing good practice. If our initial relationships with primary care, pharmacy and hospital staff are positive, other approaches to work in partnership will be viewed positively.

In detailing the work done throughout Scotland, the guide gives solid background material to:

- help to promote the joint working with health practitioners as effective partners
- raise awareness of the issues to consider when planning the initiatives
- give you inspiration to develop further, knowing you have the examples of other centres successfully working in partnership
- anticipate referral levels and costs
- enable you to phase developments within existing resources
- help to demonstrate what can be done by collaborative work
- highlight benefits to carers
- enable practitioners to understand the range of methodologies available and the anticipated costs and benefits of the different approaches.

## BACKGROUND INFORMATION

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. It is estimated that there are around 600,000 carers in Scotland. In 'Scotland's Census 2001', 115,675 people had caring responsibilities for over 50 hours a week. This covers a wide continuum of care giving and may include moving and handling, help with feeding and personal hygiene or administering medication. As a direct result of their role in undertaking these activities, carers can experience physical injury or stress-related illness.

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 because they are not in receipt of services. They may not be known to the local carers' services.\* Because of this lack of contact, they may be unaware of the services and sources of help available to them.

\* A carers support and development worker based in primary care has found 87% of the referrals received, mainly from other members of the Primary Health Care Team, have had no contact with a carers' organisation (McIntosh 2001)



# Introduction

## Researching the need

The Princess Royal Trust for Carers carried out a survey in 2001, 'Carers Speak Out', to determine the extent of need and the level of help, advice and resources available to carers. This was the most extensive survey of its kind in the UK, and received responses from 3800 carers – an almost 50% return.

The survey found that despite the 'pressing need to be directed to sources of information, help and support, around two in ten carers who began caring in the past two years, were still not directed to sources of information and support.'

Their recommendations included areas that would reinforce the importance of the Focus on Carers Initiative and support the practice set out in this publication, such as:

- the creation of discrete case tagging in practices, to inform staff of any patients who are known to the practice to have caring responsibilities. This information would assist new staff and help inform the content of the practice patient list
- publicity and awareness-raising across statutory services
- Government earmarking of funds for local authorities, health organisations and voluntary bodies to provide a carers' information strategy.

The study specifically urged that:

- carers awareness-training programmes should be available for health and social care staff
- Primary Care Trusts should work with carers' organisations to establish initiatives to support carers
- Strategic Health Authorities should encourage GP practices to develop carer support initiatives.

Following an extensive report of the 'Carers Speak Out' survey, a Good Practice Guide on consultation was produced to disseminate the lessons learned.

## Driving the initiative

Princess Royal Trust Carers Centres provide a wide range of information and support services to carers, including access to services from other agencies. Although centres work closely with statutory and voluntary service providers at a local level, the number of carers being referred to centres from health practitioners remains relatively low. The most recent General Household Study (Rowlands and Parker 1998) shows that 60% of carers had no regular visits from any of the main service providers.

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.

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 to develop methodologies to identify and support carers.

## GP AND PRIMARY HEALTH CARE INITIATIVE

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. A series of consultation meetings took place with key agencies including the British Medical Association (Scotland), the Royal College of Nursing, the Scottish Executive, Primary Care Trusts, Social Work and Princess Royal Trust Centre Managers. The outcome of this consultation was the establishment of a Task Force funded by Prudential plc, and chaired by Colin Williams, Director

Scotland, PRTC. This Task Force, which has an on-going role, supported the principles and values, and gave practical support to the initiative.

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
- provide carers 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.

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

## PHARMACY INITIATIVE

In January 2001 the Royal Pharmaceutical Society in Scotland hosted an event at the Palace of Holyroodhouse. The society agreed to work in partnership with the Trust and to forge a strategic alliance aimed at stimulating the active involvement of pharmacists in finding hidden carers who could be helped by local Carers Centres.

In recognition of this and of the important role which community pharmacists have within the healthcare system, funds were provided by the Scottish Executive to pilot the initiative and a Steering Group was formed to advise on the implementation and to monitor the outcomes. Membership of this Steering Group included representatives from the Scottish Executive, the Secretary and other members of the Royal Pharmaceutical Society (Scotland), the Chief Pharmacist of Greater Glasgow Health Board and The Princess Royal Trust for Carers.

In May 2001 the initiative was piloted by five community pharmacists together with local Carers Centres in Borders, Fife, Edinburgh, Glasgow and Dundee.

Based on the success of the pilot work in Scotland, the Scottish Executive provided additional funds to stimulate further developments. In October 2001 a repeat of the exercise was carried out with four of the five centres originally piloting the work. This has now been extended further. Currently 60 pharmacies are, or have been, involved with support from Carers Centres.

A significant development throughout the UK is now possible through the strategic partnerships agreed with Moss and Unichem.

## HOME FROM HOSPITAL INITIATIVE

Carers' experiences of the NHS and in particular their experiences of hospital

discharge (Holzhausen 2001) highlight that:

- carers' views should be sought about discharge arrangements
- carers should be consulted and involved in planning the discharge
- patients should not be discharged until the appropriate support is in place in the community
- carers who are about to provide substantial amounts of care should be offered an assessment of their needs, as reflected in the Community Care and Health (Scotland) Act 2002
- patients and carers should be given a written copy of the discharge plan.

However, it has been found that once admitted to hospital, individuals and their carers often feel dis-empowered, unable to put their point across and unsure about what is happening. In addition, an extended stay in hospital often involves possible risk of infection, and loss of confidence and independence, leading to unexpected difficulties later in the admission. These issues can be reduced if there is early contact and an acknowledgement of their worries and concerns.

It is now becoming accepted that 'discharge is a process not an event', and must be planned for at the earliest opportunity to ensure that the patients and their carers understand what is happening and are able to contribute to care planning decisions as appropriate.

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).

Carers who are involved in discharge planning should:

- feel part of the process
- consider that their knowledge has been used appropriately
- get support in having their needs recognised and met
- be able to continue caring at home if that is their wish
- understand what has happened and who to contact if necessary.

There are indications that early discharge from hospital can have profound consequences for the carer and can increase re-admission rates for the patient. Carers highlight the importance of support within the first few weeks of discharge.

This is relevant in relation to the recommendation of the independent Carers Legislation Working Group, which calls on the Scottish Executive to consider the case for a statutory duty on NHS Scotland to identify carers, offer them information, and refer them on as appropriate.

## HIGHLIGHTING THE SUCCESSES

To date, over 10,000 carers have been identified using a range of methodologies outlined in this guide. It is vital that these methodologies are carried out with care, consideration and effective planning. But quantity is not everything, and a desire for the rapid expansion of the initiatives is tempered by the need to ensure that the quality of service is not weakened by stimulating demands and expectations which are difficult to meet. However, if additional funds were made available, it would be possible to find and support a substantial number of carers using the methodologies outlined in the guide.

# Overall guidance to planning the initiative

## IDENTIFY THE RESOURCES

Any piece of new work will have resource implications. When planning a new piece of work, it is not unusual for the motivation and enthusiasm to cause you to disregard or overlook some of the costs, and the implications for the core work.

As well as the extra financial costs of stationery, postage etc. there will be extra work to fit into the remit of many or all of the staff. After the initial intensive activity to promote and implement the initiative, there could be a steady build up of requests for support, information, visits etc. Without careful planning, existing services could become stretched, and quality of response may suffer.

- Examine your current capacity. Put some possible figures on what you feel you can cope with. Could you manage to support some 10 or 20 or 30 extra referrals per week – will you need extra resources to keep up the level of service?
- Make realistic projections of the time and money it will take to develop the initiative and integrate these into existing workloads and budgets.
- Take an increased mailing and contact list into account when forward planning work with staff and adjust workloads and budgets accordingly.
- Objectively consider how an increased carer-base will impact on current quality of service.
- Don't forget you will need extra administrative support for development and production of materials to promote the initiative, and the production of information sheets and newsletters for your increased carer base.

### Material Costs

The material costs, to the Carers Centre, for the implementation of the

GP and primary care mailshot is on average 26p for each patient contacted, not all of whom will be carers. For example a mailshot to 1,000 patients will cost an average of £260. The Pharmacy initiative has no associated cost to the centre, apart from the return postage cost (£2 per 1000 customer contacted), as the printing costs for cards and letters are currently covered by the Trust. These printing costs currently work out at an average of 21p for each customer receiving the material. So for 1,000 customers the cost would be on average £210. This material cost per centre does not take into account costs such as staff time for producing and processing the materials. Once the carers have been identified, you will also need to budget for the cost of increased numbers of newsletters, briefing information and general contact literature.

For example one centre has seen its own mailing list double because of the success of the initiative, which effectively doubles the cost of the quarterly mailout.

*'It has been really great to have all publicity materials provided by the Trust but the increased cost of our own publications and mailouts was something we hadn't considered.'*

When your initial analysis of the funding requirements has indicated the likely cost of being involved in the work, you will need to identify how it will be funded. Do you have spare capacity within existing resources? Or do you need to seek external funds? Several centres have accessed funding from local SIPs (Social Inclusion Partnership funds) and LHCCs (Local Health Care Co-operatives), whilst others have received support from funders such as The Lloyds TSB Foundation and The Community Fund. If your budget is minimal, you may

need to look carefully at current work, identifying which areas can be deferred or restricted, and using the time released to implement the initiative.

### Personnel

It is important to identify, early on, the member of staff who will be co-ordinating and undertaking this work. Where this is to be part of their existing work, the duties should not be just 'tacked on' to existing duties, but designated as a discrete piece of work. Care must be taken in drawing up the job description to ensure that lines of contact and accountability are clearly shown and also the relationship between the current post and the new responsibilities. Where there is a newly created post, the job description should have a similar clarity.

All the necessary information and contact should be done through this person, to ensure that the work is kept up-to-date and confidential. You should also be certain that your procedures for recording and accessing data are up to date and comply with the Data Protection Principles.

### REFERRALS TO OTHER AGENCIES

Once carers have been identified, and become more aware of the services and sources of support available to them, they will start to come in to the remit of other agencies. Agencies such as health, social work, housing, benefits agency and other voluntary organisations may notice an increase in enquiries and service requests.

Before you start the initiative:

- 1 Inform the agencies at an early stage that you are about to commence the work of identifying carers and this may mean additional referrals for them.
- 2 Establish clear referral arrangements with one individual from each agency as a named contact.



# Overall guidance to planning the initiative

## SUPPORT FROM THE PRINCESS ROYAL TRUST

The Trust has been able to provide a range of support to help Carers Centres establish partnership working with primary care staff and pharmacists in their area. These have included:

- guidance on the best ways of implementing the methods used to identify carers
- on-site training for those staff directly involved in identifying carers
- Trust staff attending initial meetings with primary care staff and pharmacy staff, if this is seen as helpful by the local Carers Centre
- suggestions for presentational material to support your approach to the health care professionals.

The Trust can also put you in touch with staff from Carers Centres experienced in these areas of work. This will provide an opportunity for those new to this work to learn from the experiences of other centres and to talk through anticipated challenges in their own areas.

## CHECKLIST 1

- What are the overall objectives for this work?
- Are we certain that we want to be involved in the initiative?
- How does this work fit into existing priorities?
- How are the committee / board involved in this work?
- Who will be doing the contact work?
- Who will be managing it?
- How will we integrate the initial work in current staff workloads?
- Should this be a discrete piece of work for existing or new staff?
- Is there any work that will have to be deferred or restricted to take account of this initial work?
- Do we have sufficient information material ready to cope with the response?
- Have we sufficient funds in the budget to pay for the initial materials/postage etc?
- Is this a time-limited or on-going piece of work?
- Do we have sufficient resources to cope with a significant increase in service provision?
- How will we monitor and evaluate the initiative?
- What are our criteria for success?

# GP and Primary Care Initiative



# GP and Primary Care Initiative

## CHECKLIST 2

- Your aims and objectives for the initiative
- The major benefits to the carer
- The benefits the GP and the practice can expect
- The degree of involvement from the GP and/or their staff in terms of workload time and cost
- How you will monitor the effectiveness of the work
- How and when this will be fed back to the practice
- How you will ensure confidentiality
- Who will pay for the mailings and other materials

## OVERVIEW

Research carried out by Carers UK (Henwood 1998) identified that 88% of carers had visited their GP in the previous year for concerns about their own health, as well as visiting for the person they were caring for. The research also noted that carers expected the GP to know about available help and presumed that if they were not being informed about support, then it simply did not exist.

## PREPARING YOUR CASE

GPs are busy people and are inundated with requests. They need to be convinced of the value of working in collaboration. Preparation, therefore, is a crucial element in developing partnership working with GPs and other primary care staff. Before making any initial approach to GPs or primary health care teams, you need to have worked out a fairly comprehensive plan, which includes the aims and benefits for all parties and a clear outline of what is being requested from the primary health care team and how much time it will take. Think about the questions that they may ask you, and ensure that you have some well-thought-out answers. You are aiming for maximum commitment from all concerned, and a professional initial approach will help others see you in a more professional light.

## MAKING THE APPROACH

Decide how best to target your initial approach and who best to approach in the first instance. You may wish to build

on existing relationships with a GP or community nurse or you may target specific primary care staff and services. e.g. chair of LHCC (Local Health Care Co-operative) or practice manager.

For example in one area the partnership working was targeted on primary health care staff who visited individuals in their own homes (e.g. district nurses and health visitors). This approach helped to ensure that those carers who did not get out and visit the health centre or GP practice would still be able to get information about the local Carers Centres and available services. It also ensures that key workers are aware of and cultivate established links with the Carers Centre.

If you already have established relationships with a GP, practice manager or district nurse, you may wish to focus on their practice initially. Once the initiative is successful in one site, other GPs may come on board more easily. In addition, some of the GPs who have experienced the benefits of working with Carers Centres to identify carers, have 'spread the word' about identifying carers to their colleagues.

*'It was great to start the Focus on Carers work in a practice where we already had a relationship with the GP, because he knew what we did and valued it. This meant he was ready to listen to our suggestions for developing that relationship.'*

One centre made a direct approach to the local GP committee, making a presentation and providing packs

detailing the aims and objectives of the initiative. This led to a GP making contact with the centre and the initiative being established successfully in that practice. It has since gone on to build on that success and develop partnerships in other practices in the area.

## PRESENTING THE CASE

### Direct contact with the GPs

If the initial point of contact is the GP you will need to make a concise presentation covering the aspects already identified. The overheads, supplied by The Princess Royal Trust, detail the salient points of the work including the aims and objectives, the benefits for carers and patients, GPs, primary health care workers, and other community care staff. This can be adapted to include local circumstances and statistics and can be delivered effectively in a short period of time. A copy of the overheads is given as an appendix and is also available from the Trust's website on [www.carers.org](http://www.carers.org)

### Working with the practice manager

If the point of contact is the practice manager and/or the wider primary care team you may be asked to make the presentation at a team meeting, which will provide the opportunity of dealing with any concerns that the practice may have. This approach provides a good opportunity to ensure all staff are given appropriate details of the work involved in identifying carers at an early stage.

### Making the agreement

Regardless of which member of staff you approach initially it is important to remember that the agreement and support of the GP or GPs is crucial in ensuring that the relevant time and importance is attached to the initiative by other staff. This means ensuring that they formally commit themselves to taking part in the initiative, possibly with a written agreement.

It may be useful at this stage to present as wide a range of options as possible. But be certain that your centre is capable of supporting those you are promoting, and that you are not over-committing your resources.

Once a clear agreement has been reached with the GP or practice manager, further awareness-raising will be required with the rest of the staff where the initiative is being implemented, either through one-to-one contact or through a presentation. Recent research has shown the importance of all staff in primary care settings being committed to, and aware of, the initiative, including reception staff (Stewart 2002). Reaching as many staff as possible will maximise the numbers of carers reached.

## METHODOLOGIES

### What will work best for you and the local GP practice

There are many ways of reaching carers who have contact with the various health professionals within a practice. Your previous analysis of the resources necessary, and an identification of those currently in your centre, should give you an idea of which areas of the initiative you can effectively tackle.

### Mailshot identification

#### LIKELY PROJECTED COSTS

From 2000 mailings you could expect a 6% return = 120

Material costs = £520

Other admin costs for production and processing of material and information

A pattern has emerged which indicates that around one third of all carers identified will request immediate support

- This method identifies carers through the use of a letter and short questionnaire 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.
- It ensures that all these patients receive direct communication, even those who are not able to get out and visit the health centre or practice. However, it is important to stress that it is only carers that are being asked to respond to the questionnaire.
- The practice is asked only to generate a mailing list, which can be based on a range of factors such as age, gender or nature of illness, e.g. stroke or heart disease. Names and addresses of patients are never removed from the practice.
- The Carers Centre staff provide the practice with sufficient questionnaires and photocopies of the form letter from the doctor on practice-headed notepaper. This letter is then signed by the GP to show that this approach is approved and supported by him/her.
- The centre may pay for all the postage if necessary, but this may be open to negotiation with the practice.
- Practice staff are asked to put on the address labels in order to maintain confidentiality.
- Reply-paid envelopes are provided for return either to the GP practice or to the Carers Centre.
- Clear confidentiality guidelines should be agreed and observed throughout the above process.

Guidelines for the mailshot and a pro-forma letter and questionnaire are given in the appendices and are also available for download on the PRTC website at [www.carers.org](http://www.carers.org)

The number of letters sent out is recorded. When evaluating the success of the initiative, it is important to realise that the normal response rate for unsolicited mailing is between 3 and 5%. The common response rate for this initiative has been on average between 4 and 9% throughout Scotland, although in some areas it has been substantially higher.

Once the questionnaires are returned, remember to:

- add the new names to the Carers Centre mailing list
- contact those carers who have asked to be contacted personally
- send a letter and Carers Centre information pack to all other carers
- record the number of questionnaires returned
- collate, record and evaluate the information from the questionnaire
- pass the information regarding the carer to the practice for patients' records (with the patient's consent)
- destroy the questionnaire
- record and measure the outcomes in terms of referrals to the centre and resulting benefits to carers.

This method of identifying carers is relatively easy to implement and practice staff have acknowledged that it does not involve them in much additional work. It can be used in a number of settings where it is not practical to undertake on-site work.



# GP and Primary Care Initiative

## CASE STUDY PRTC Dumfries and Galloway Carers Centre

The centre used the mailshot approach with two separate local medical centres, Lochthorn and Newton Stewart, where the target groups were 455 patients of both sexes between the ages of 35 and 60 years and 1100 female patients aged between 40 and 60 years respectively.

The methodology was the same in both cases.

A personal letter from the GPs was sent to each of the households in the practice, accompanied by a questionnaire provided by the Carers Centre. The letter explained the importance of identifying carers and that the practice was working in conjunction with the local Carers Centre to provide support to those caring for a relative or friend.

All respondents received a letter from the Carers Centre thanking them for returning their form, together with information about the Carers Centres services. Where requested, respondents were added to the centre mailing list to ensure that they receive information on a regular basis.

## Responses

Medical Centre	No. of Patients	Returns	%	Request for immediate help	%
Lochthorn	455	18	4.0%	6	33.3%
Newton Stewart	1100	103	9.4%	39	37.9%

Statistical information provided by PRTC Dumfries and Galloway Centre

Carers who requested follow-up contact received information and advice about:

- benefits
- social work assessments and services available
- occupational therapy assessments and equipment available
- funding and grants available.

One-to-one support was also needed by a number of carers, whilst others accessed specific support, such as the male carer support project and the young carers project.

A written report, detailing the number of carers identified and the outcomes for those carers, was sent to the medical centre involved.

A list of carers identified during this project, and who gave permission for their details to be passed to their GP, was made available to the medical centre with the opportunity to mark the patient's file as having caring responsibilities.

## Caution

Not all practices have the same recording systems and this means that it is much easier for some practices to identify illness-specific groups or age and gender groups than others. Discuss with the practice which method is more appropriate to them. If they cannot get this information easily they may not be attracted to this method.

## On-site identification

### LIKELY PROJECTED COSTS

Material costs minimal – photocopied questionnaires and occasional SAE /freepost envelopes.

Staff time could be 10+ hours per week interviewing potential carers, + processing the information.

- The objective is to identify carers within a specific practice and help them to get access to information and support, in response to their own particular needs.
- This method of working places centre personnel 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.
- If they identify themselves as carers, they are invited to complete a short questionnaire, which asks for basic information about their situation and what services or information they would like from the Carers Centre, ranging from being put on the mailing list to requesting specific services.
- If this is not completed at the practice, they are given a stamped addressed envelope (or freepost envelope) to return to the centre.
- The questionnaire also seeks the permission of the carer to advise the

GP that they are a carer. This means that at the end of the on-site work the patient's file can be tagged either with a sticker or electronically, alerting the people assessing their notes to the fact that the patient has caring responsibilities.

A standard questionnaire is provided in the appendices which can be adapted to meet local needs or translated into other languages or formats.

This approach can offer an opportunity to discuss issues directly with carers, although the extent of this will be determined by the availability of confidential space within the practice. Also, be aware that some patients – who may or may not be carers – will feel threatened or upset by a direct approach, and so care must be taken when planning this approach.

This method is also valuable in that it can provide information on carer status to GPs to update their own information system, as well as building relationships with staff throughout the primary care team.

#### **CASE STUDY** **PRTC Fife Carers Centre**

The centre had two dedicated carer support workers based in the GP surgery carrying out the on-site approach, with the initial contact being made with the practice through the centre manager.

It was felt to be very important to establish and develop the relationship, before the implementation of the initiative was underway. One approach that worked especially well was, by invitation, to visit the practice at break-times, so that the centre staff were able to talk to the practice staff informally and become known to them as a part of the team. This was also an opportunity to address any concerns or questions that

arose, and to assure the practice staff of the centre's professionalism and protocols, especially in the area of confidentiality.

The centre has had excellent feedback from the practice regarding the success of the initiative and uses this feedback to encourage other GPs to participate in the initiative. Indeed the centre manager has had GPs phoning to ask if their own practice can be involved in the initiative.

#### **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.
- 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.

The presence of the carers' support worker, raises the profile of carers' issues with all staff in the practice, highlights the services available and promotes the centre worker as part of the extended team.

#### **Caution**

Although a significant amount of positive and productive results have been gained from the approach, not all of the relationships have been successful. On one occasion, a centre manager had made a verbal agreement with the senior doctor that the centre's development worker would carry out on-site identification in the practice. However, this arrangement was not

communicated to the other staff. When the development worker arrived with leaflets, questionnaires etc. the receptionist and other staff questioned her authority to be there, and would not allow her to stay. In another case, the development worker was allowed in the waiting room, but was not allowed to approach the patients, but had to wait for them to approach her.

Preparation and confirmation is the keynote to effective relationships, so always:

- draw up a written agreement between the centre and the practice setting out the scope of the work
- ensure that practice staff have been informed what you are there to do
- be sure the agreement allows you to speak freely to patients.

#### **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.

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

##### **LIKELY PROJECTED COSTS**

Costs incurred for professionally presented promotional and information material, either printed by the centre or commercially. Staff time to update all material.

You can use notice boards or publicity material to highlight carers' issues and ensure there is a consistency of information provision



# GP and Primary Care Initiative

for carers who visit any health setting. An effective and up-to-date notice board or publicity pack will ensure that carers who have not otherwise been identified will, at a minimum, have a point of reference for further information when and if they require it.

This does, of course, rely on the carer – or care recipient – taking the initiative to read and/or collect the material.

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

A number of options can be considered for the use of publicity material.

- One site can be used, e.g. waiting room table.
- The material can be offered in different formats throughout the practice such as cards being placed at the reception desk with leaflets

displayed at a central point.

- To highlight your information on a notice board displaying information along with other organisations, create a border around your material to make it stand out.
- Compile a carers' information pack and leave this in the practice where it is clearly visible and accessible for patients to refer to whilst in the practice. As it can be difficult to ensure that a pack does not get lost amongst other material in the practice or taken out of the health centre by a carer requiring support, it is important to check and update the pack regularly.

A regular presence is desirable so that all carers, whether or not they make contact, should know how and where to get support should they require it. This consistent availability of relevant material has also led to a number of health service staff

identifying themselves as carers requiring information and support.

**Remember** All publicity material must be kept up to date, so build in time for updating and checking its availability and accessibility to patients. The case study below illustrates the value of providing material appropriate to the particular group of carers you are aiming to identify.

### **Positive Feedback**

A survey of GPs involved in partnership working with Carers Centres undertaken by the Trust in May 2001 found that 26 of the 30 GPs who responded felt that the publicity material used was an effective method of helping patients identify themselves as carers and of raising awareness of carers' issues more generally.

One practice manager observed that *'patients notice when new material appears on the board ...'*

### **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.

## Direct awareness-raising

### LIKELY PROJECTED COSTS

Significant staff time to establish and maintain the relationship with the primary care team. There will also be staff time in following up on support needs of any carers referred.

Material costs according to number of questionnaires issued. No outward postage to pay for, but add cost of all freepost returns.

Carers Centre 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. Staff can also make direct referrals to the Carers Centre. As a

result of their regular visits to patients, community-based nursing staff are often aware of who carers are. It is important to maintain the links and continue the contact if you wish to sustain the awareness of carers' issues. As with other approaches, you should be measuring the outcomes in terms of referrals to the centre.

The same procedures should be applied for recording and responding to referrals received through this mechanism and for providing feedback to the relevant staff including thanking them for their involvement.

### Variations

Direct awareness-raising can also take place when advising other agencies such as local authority community care teams that the identification of carers work is taking place. This allows Carers Centre staff direct access to other staff who also undertake home visits.

Raising and maintaining their

awareness of the services available should increase the number of carers identified.

### CASE STUDY

#### Family Medical Group and the Princess Royal Trust Dundee Carers Centre

Each member of the practice and attached staff was asked to examine their workloads in terms of identification of carers over a month. All staff were asked to participate and each member of staff was allocated funded and protected time to identify carers.

For some staff this meant an examination of their current caseload. For GPs and practice nurses it meant 'thinking carer' for every contact with a patient/relative no matter what the type of health issue being addressed in the consultation/appointment. For the reception and

administrative staff it was their extensive knowledge of patients and their individual circumstances that was established, confirmed and used in identifying carers who regularly use the surgery services.

The busy workloads of all primary care staff meant that it was not always possible to consider every contact as a possible carer and as a result in the first two weeks only a small number of carers were identified. It was decided that some form of prompt was needed, and for the final three weeks reception and/or administrative staff had attached one of the referral forms to every set of medical records for every patient appointment. This greatly increased the numbers identified.

# 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.

## 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 reply card put into each prescription bag

collected by the customer over a time-limited period.

Materials needed are:

- a letter from the pharmacist explaining the initiative
- a pre-paid reply card to be returned to the Carers Centre.

### LIKELY PROJECTED COSTS

From 2000 cards distributed you could expect a 1% return = 20

Material costs = £420

Minimal costs in processing of material and information.

Some centres have reported significant staff time to develop and maintain relationships with pharmacies, others have not.

## Preparing the ground

Although the initial preparation for this particular approach to identifying carers is probably less intensive than with the approach to GP practices, it is nonetheless vital that you are quite confident that the processes are in place before implementation. Look again at **checklist 1** (page 10) to ensure the various discussion and decision stages have been completed. As with the GP initiative, you must be sure that you have sufficient resources to cope with the extra work, and capacity to cope with the potential follow-up work without sacrificing quality of service.

## CHECKLIST FOR INITIAL AND CONTINUING CONTACT

An initial approach should be made to the pharmacist, which should include details of

- the benefits to carers
- the work of the Carers Centre and the types of services offered
- the background to the initiative, including an indication of the support given by the Royal Pharmaceutical Society in Scotland or other appropriate bodies
- your proposal regarding the work to identify hidden carers including the proposed time scale and duration of the initiative
- its success rate in the initial and secondary pilots
- the types of services and support available to carers from the pharmacist, such as training on the safe and secure handling of medicines
- the benefits to the pharmacy of working in collaboration with the Carers Centre.

When meeting with the pharmacist to discuss the potential for partnership

- be prepared for questions from the pharmacy staff and ensure you have enough information to answer them
- confirm the maintenance of confidentiality both in accessing and storing all information gathered, especially that which may be regarded as sensitive
- encourage all pharmacy staff to be included in the briefing
- emphasise the need for literature to be included in every repeat prescription bag
- take copies of the letter from the pharmacist and reply post card
- check the initial number of copies of letter and post cards needed, based on the pharmacist's estimates of individual patient numbers (remember this is based on the number of prescriptions NOT the number of items prescribed)
- leave a copy of 'Are you a Carer?' poster to be placed in a prominent

place in the pharmacy to increase the impact of the initiative.

When getting the initiative underway

- confirm the arrangements made at the initial meeting
- agree timescale for implementation
- make an accurate note of the numbers of cards/letters left at the pharmacy, to be set against the number of returns
- indicate when you will make future contact
- check that the poster is being displayed.

Follow-up contact with the pharmacy at regular intervals to

- check their supply of literature
- update them on the number of returns
- give them an overview of the types of services being accessed
- find out if the staff have any questions and concerns and what you can do to address them
- thank them for being part of the initiative.



# Pharmacy Initiative

## 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.

## Keeping records

As the postcards are returned:

- record number returned
- add new names to the Carers Centre mailing list
- contact carers who have asked to be contacted personally
- send a letter and Carers Centre information to all other carers
- collate the information from the postcards.

The number of carers responding to the literature placed in the prescription bag has varied greatly from centre to centre and also around the various regions of Scotland.

Although many centres reported that the majority of carers who responded were often happy just to be on the mailing list, some have mentioned complex and high-end caring responsibilities needing quite intensive immediate and on-going support. Where carers only requested to be put on the mailing list, centres have sent details about the centre and other available services, rather than waiting until a newsletter was due. This initial contact often included an invitation to contact the centre by phone or to come in personally.

In all instances, contact details were entered into the current database, and those requesting immediate help and advice were referred to relevant centre staff.

Although it is difficult to predict precisely the levels of carers identified, patterns are emerging, which indicate that the average will be 1%.

There also seems to be a consistent average of two thirds of those identified needing no immediate help as against one third needing a variety of support systems, such as:

- advice about assessments
- information about mobility or other aids
- information about respite care
- help with benefits
- home visits
- emotional support.

## Positive feedback

A pharmacist from a rural area explained that he had taken part in the pilot in order to promote a professional image of the pharmacy service and provide a holistic care service to the patients and carers. He was extremely satisfied with the outcomes and felt that the level of newly identified carers more than paid back the small effort that was expended.

This sentiment echoed that of two centre managers who stated:

*'If I were asked, in the future, to take part in just one initiative to find hidden carers, I would definitely go down the pharmacists' route. It's well worth the effort for such a good return.'*

*'This was a really easy initiative for us. The Princess Royal Trust had prepared the ground by going in to the pharmacy and telling them all about it, so they were quite motivated by the time we met them all. I think part of the success was that the pharmacists we worked with really cared about their customers and so they saw it as a natural part of the service they provided.'*

# Home from Hospital Initiative



# Home from Hospital Initiative

## OVERVIEW

The Home from Hospital Initiative is based on a recognition that when patients are discharged from hospital following an accident or acute illness such as a stroke or heart attack, a member of their family, a friend or a neighbour will be taking on some or all of the duties of a carer, often for the first time.

This point is therefore an important opportunity to identify and support carers at the start of their caring responsibilities.

However it is also acknowledged that an acute change in circumstances, such as a period in hospital, may reinforce the need to inform existing carers of resources and services available from local voluntary and statutory agencies.

## Development of the initiative

Two Carers Centres, in the Lothians and Ayrshire – have set up home from hospital initiatives, providing support and advice for the carer during and after the hospital stay.

The initiative ensures that carers of people leaving hospital are aware of the services available, and have immediate access to their local Carers Centre and other support systems. This has included the production of ward discharge packs for carers and on-site availability of Carers Centre staff in acute hospital settings.

## PRTC EAST AYRSHIRE CARERS CENTRE

Funding for this initiative was obtained initially by the Carers Centre from East Ayrshire Council to fund the hospital packs, and then from Princess Royal Trust Development Funds through the Moffat Foundation who funded the part-time hospital post.

## CASE STUDY

### PRTC East Ayrshire Carers Centre

An introductory letter was sent to the hospital manager setting out the benefits and context of the initiative. Following an enthusiastic response, a number of meetings were held with representatives from East Ayrshire Council Social Work Department, Ayrshire and Arran Health Board and staff from the Carers Centre. Issues such as funding, staffing, publicity material, monitoring and evaluation and operational procedures were agreed.

The hospital manager was part of the steering group established to develop the project. He felt the initiative would assist hospital staff in dealing with enquiries from patients and their relatives regarding financial assistance, aids and adaptations, social services and respite breaks. It was felt that this information should be contained in an easy to read pack and a first draft was compiled and distributed widely for feedback. Eventually the Home from Hospital Pack was produced, which was to be given to patients and/or their carers prior to discharge. Included with the information was an addressed card to return to the Carers Centre if the carer wanted more information or support. Primarily, requests have been for home visits, financial information and advice on welfare benefits.

Initially a member of the centre staff visited the hospital regularly but the initiative did not become established until a dedicated worker (10hrs/week) was in post. This ongoing contact built up relationships with the staff to raise their awareness of people with caring responsibilities. The contact worker has a medical background so has credibility with the hospital staff who see her as a colleague who understands their difficulties.

A mixture of new and existing carers have been identified. The initiative has been actively publicised and promoted with details displayed on the information screens around the hospital. The first event was a launch of the information pack to raise the profile of the initiative. Notable milestones have been celebrated. The first was 100 carers identified, then 500, and plans are in hand to celebrate the 1000th carer. There is also a regular feature in the hospital newsletter.

In the first three and a half years of its existence the initiative has resulted in 800 carers being identified through this direct work in hospital settings – 450 for Kilmarnock and 350 for North Ayrshire. Those referrals outwith the East Ayrshire Centre catchment area are passed to the other participating Princess Royal Trust Centres.

## Benefits to carers and patients

The initiative

- provides information regarding community care services and how to access them
- provides carers with support at the point of discharge by helping them to make effective choices about their involvement in future care arrangements
- allows carers the opportunity to consider their own health needs
- encourages carers to seek out information which will help them to be more effective in their caring role.

## Benefits to hospital staff

The initiative

- supports good practice when planning discharge, by encouraging recognition of carers and their role in providing care
- increases access to specialist support services to which they can refer carers for information, support and advice

- increases links with the community and access to the local community services.

#### Tips from this initiative

- make initial contact with the hospital manager, or the person who has authority to help drive it forward
- a dedicated post for this work will prove more effective to keep the interest in the initiative alive
- make yourself known to the staff in as many wards and departments in the hospital as possible
- keep up the momentum with high profile events/publicity
- provide comprehensive information in an easy-to-read, but professional format
- initial contact should be made with carers at point of admission rather than at discharge
- information should be available during the hospital stay, to enable the carer to prepare for discharge.

#### PRTC VOCAL (Voice of Carers Across Lothian)

The experience of VOCAL has many similarities with East Ayrshire in the ethos and implementation of the initiative. In partnership with NHS Lothian, VOCAL has been involved in the production of an information pack entitled Home from Hospital to 'assist patients and their families and carers to smooth the journey from hospital admission to subsequent community care support at home'. This publication was developed with the involvement of over 60 carers

and practitioners in the Edinburgh and Lothian NHS area.

Following an initial pilot, the NHS provided funding for 25,000 copies for distribution to all hospital wards and Primary Care Centres in Lothian, starting in June 2002. A further commitment of £38,000 has been given by NHS Lothian to support the future development of this work.

The pack is available in four of the most common minority ethnic languages, Braille and large print and contains information on:

- what people can expect to happen when a person is discharged from hospital
- services to support the carer and cared-for person
- contact points for more detailed information and further support.

The information is divided into six separate sections:

- 1 Before leaving hospital – discharge planning
- 2 After leaving hospital – services in your community
- 3 Finance – costs and benefits
- 4 Being a carer – support for you
- 5 Where now? – useful contacts
- 6 Checklists – asking questions.

The packs have proved very popular and their effectiveness is now being evaluated. A report will shortly be produced on this work by Alison Jarvis, Lecturer, School of Nursing Studies, University of Edinburgh.

This working partnership between VOCAL and NHS Lothian 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.'*

# Monitoring and evaluation

## MONITORING

*'Regular checking of progress against a plan of action through systematic collection of information, which is often statistical' (Connor 1993)*

### OVERVIEW

Clear monitoring procedures are essential to enable you to check that the initiative is working effectively and having an impact, and these procedures should be an integral element of whichever method of identifying carers you select. Monitoring information is also essential to allow you to give feedback to the participating health service staff. Simple but comprehensive monitoring and recording systems must be in place before embarking on any piece of work.

The monitoring arrangements should include a systematic recording of a range of factors, although these will vary depending on the method of data collection employed. A simple 'rule of thumb' in determining the most appropriate methods, is to decide:

- what information/data you need to have
- why you need to have this information
- who is to be responsible for collecting and recording the data
- what you are going to do with it
- how you are going to store and make it available for retrieval
- who will have access to this information
- how long you will be collecting the data.

### DATA COLLECTION AND COLLATION

With particular reference to the GP mail-shot and on-site methods, it is important to record the following in

order to obtain an accurate response rate and assess the effectiveness of the method used:

- the method used to identify the carer
- the number of questionnaires issued
- the number completed and returned
- the source of the returned questionnaire i.e. where the carer got the questionnaire.

From the questionnaires you will collect data regarding:

- the GP practice or setting they were identified from (the carer may be registered with another GP practice but visiting the surgery to collect a prescription)
- age and gender of carer
- the nature of the caring situation
- whether Social Services are aware of the caring situation
- whether the carer's GP knows they are a carer
- what kind of support the carer or cared for person requires
- the outcome of any support provided, e.g. benefits or services received.

In cases of several identification methods being employed at one time, questionnaires can be colour coded to evaluate at a glance which methods were identifying how many carers at any particular time. However, be aware that there may be some differences in perception of colours and so a numerical reference at some place on the page would be useful.

### EVALUATION

In making comparisons between the various methods, intensity of effort and results achieved, it is vital that there has been some indication of the

*desired* results. For instance, was there a target or limit set on the numbers of carers to be identified, was there a time limit for the work or was it open-ended? You must also consider the implications for current and future work, both in terms of finance and the staff and committee workload. Are you able to evaluate the loss to the centre of any of the work that had been put on hold to allow implementation of the initiative? In short, has it been worth the effort?

### USING THE INFORMATION

One of the prime reasons for gathering information is to provide feedback to your health service partners regarding the outcome of the work. This information is vital in detailing and highlighting the benefits to carers. However, some indication of the benefits to the partners will contribute to the strategic development of further partnership working, enabling you to negotiate further work with the same practice, pharmacy or hospital, or move more effectively to other partnerships in the area.

Just as importantly, clear monitoring allows your centre to determine the most effective methods for identifying carers in their own area. This information can be used to show how the centre has developed its partnership working by indicating what worked and what didn't.

### MEASURING OUTCOMES AGAINST INPUT

As well as measuring and evaluating the quantitative results of the initiative, i.e. how many hidden carers have been identified, it is important to review and measure the input of effort and resources that influenced the results. It



# Monitoring and evaluation

is easy to forget, or to absorb pieces of work into the day-to-day activities, unless there is a simple recording system such as a day planner. You can use this to indicate, in 15–30 minute slots, where you are carrying out a particular piece of work for the initiative. As well as the easily recorded activities such as meetings etc. remember to note telephone calls in and out, writing and answering letters, compiling databases and other administrative duties. This should help you to calculate items such as:

- 1 How much time per week/month has been *directly* expended on the initiative?
- 2 How much time per week/month has been *indirectly* expended on the initiative?
- 3 The *real* cost of materials/postage/telephone etc.

This information will help when making decisions about continuing or extending the work.

# Further reading



## Further reading

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Further information, which is regularly up-dated, can be found on the PRTC website at [www.carers.org](http://www.carers.org) Scottish Executive documents can also be downloaded directly from [www.scotland.gov.uk](http://www.scotland.gov.uk)

# Appendices



# Appendices

## THE DATA PROTECTION ACT 1998

In view of the amount and type of data generally held by a carers centre it is vital that there is a formal process to gather, store and retrieve that data.

Recording procedures should be in line with the values and structure of the centre's own confidentiality policy. They should detail exactly how the information is gathered and recorded, ensure that it is held securely in line with Data Protection guidelines, with access available only to those who have a right to view it.

Remember that although individuals have a right of access to any information held in written or computer format, information supplied by an outside party, such as doctor or social worker, cannot be disclosed without the permission from its author.

The Information Commissioner (an independent supervisory authority reporting directly to the UK Parliament, enforcing the Data Protection Act 1998) maintains a public register of data controllers. Individuals can consult the register to find out what processing of personal data is being carried out by a particular data controller. Notification is the process by which a data controller's details are added to the register.

The Data Protection Act 1998 requires every data controller who is processing personal data to notify unless they are exempt (but they must still comply with the Data Protection principles).

## DEFINITIONS

*Manual data* is data which is part of any relevant filing system. (In other words, it covers paper records as well as computer records).

*Personal data* means data relating to living individuals, which allow them to be identified.

*Sensitive personal data* is a new category, and includes personal data about, among other things, racial or ethnic origin and physical or mental health or condition.

*Data controller* is the organisation (not the individual within it) in its capacity as a collector of information.

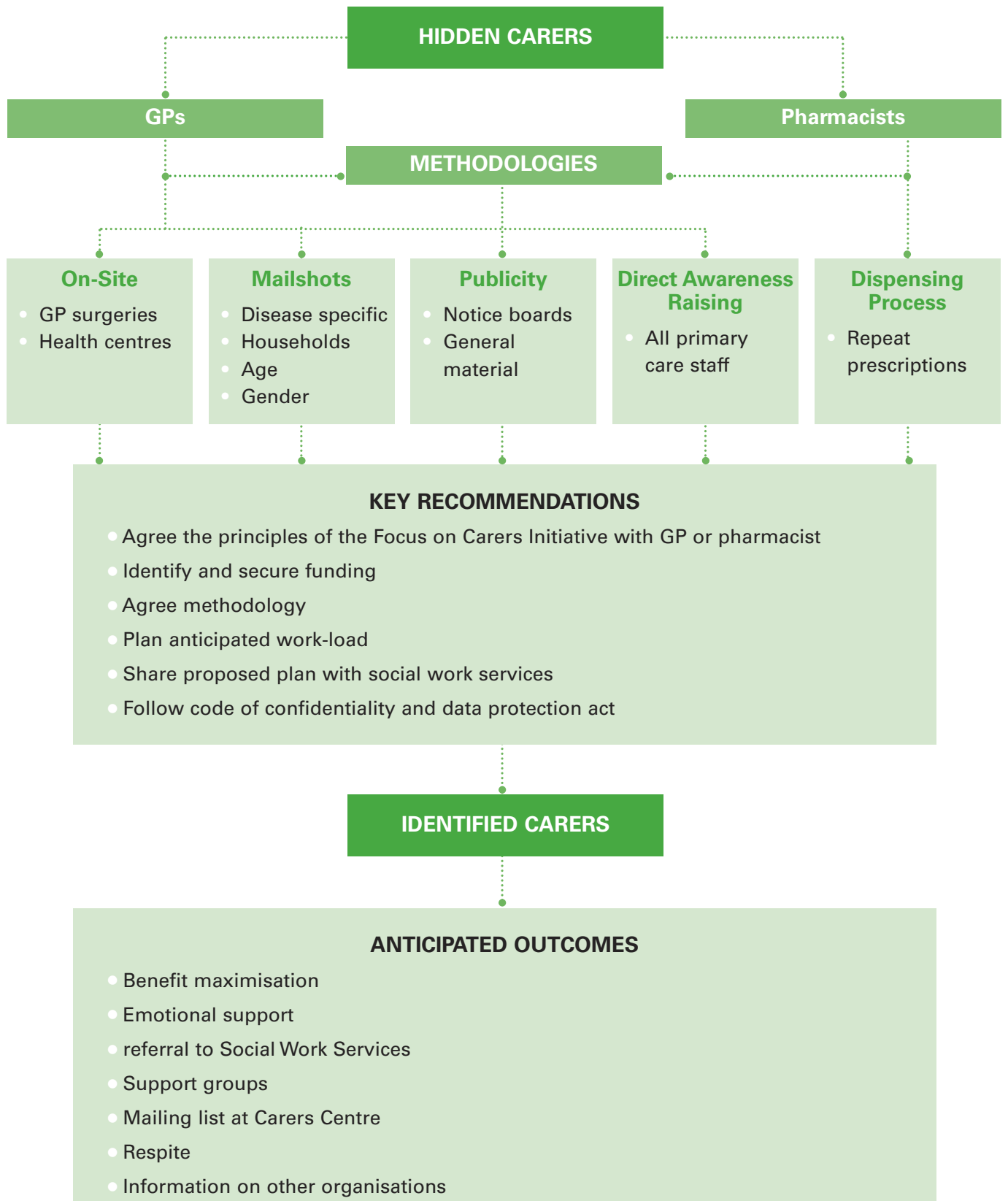
## GENERAL POINTS

1. It is important that all individuals act under the rules of the organisation, otherwise they could become Data Controllers in their own right and therefore subject to notification.
2. If you hold information about people they must know who you are, why you are holding the information, and what you are doing with it. If it is obvious, you don't have to tell them explicitly, but it is good practice to err on the side of caution.
3. Once you have obtained information, every use you make of it must be 'fair', and you must only use it for the purpose(s) for which you obtained it.
4. There are some circumstances when you need consent to use people's data. For 'sensitive personal data', consent may be required. In other circumstances it is good practice to get consent whenever possible.
5. You must take care of people's data. This means preventing people (including your own staff and volunteers) from seeing data they are not authorised to, and taking care not to lose data, which may include backing up the information and storing it separately.
6. When you disclose data you have to be sure that the person you give it to has a good reason for getting it (i.e. compatible with the purpose you obtained it for), and that they are authorised to have it.
7. People have a right to see the information you hold about them,

including any information that is recorded on paper files.

8. Any unsolicited contact, such as information about your centre, MUST give the recipients an opportunity to refuse or opt out.

More general information is available on the Data Protection website [www.dataprotection.gov.uk](http://www.dataprotection.gov.uk) and the helpline is on 01625 545 745.





# Appendices

## **FOCUS ON CARERS INITIATIVE**

### **Mailshot Guidelines**

*All information obtained should be treated as confidential. Patient lists must not be taken away from practice premises.*

#### **Mail to patient in C5 envelope:**

##### **GP letter**

##### **questionnaire**

##### **return envelope, either freepost or add 2nd class stamp**

#### **Method**

1. Prepare draft letter for GP's approval and signature(s).
2. Photocopy agreed number on practice notepaper.
3. Photocopy questionnaires.
4. Prepare envelopes for return of questionnaires to either  
Health Centre – address and 2nd class stamp or  
Carers Centre – freepost details if available or address and 2nd class stamp.
5. Address by hand or attach computer labels.
6. Check postage weight or an envelope for the correct postage charge. Apply appropriate postage stamp(s) or frank.
7. Record number of envelopes sent out.

#### **RETURNED questionnaires:**

1. Add names to CC mailing list checking for carers already known to centre.
2. Telephone carers who have ticked the box on questionnaire asking for contact.
3. Send a letter and CC information to all other carers.
4. Record number of questionnaires returned.
5. Collate information from questionnaires.
6. Give questionnaires to practice for flagging up, including applying carers stickers on records, if required.

## DRAFT LETTER FROM GPs TO ACCOMPANY QUESTIONNAIRE

ON GP HEADED PAPER

Date

Dear [Patient's name],

Our practice is currently working in partnership with The Princess Royal Trust ..... Carers Centre to offer support to patients of any age who have caring responsibilities for someone who is ill, disabled or elderly.

We are interested in identifying carers who may be unknown to this practice or other statutory agencies. Sometimes these 'hidden' carers are looking after a family member or helping a friend or neighbour with day to day tasks and may not see themselves as a carer.

We feel that caring for someone is an important and valuable role in the community, which is often a 24-hour job that can be very demanding and isolating for the carer. We further believe carers should receive appropriate support by way of access to accurate information on a range of topics such as entitlement to benefits and respite care and not least, a listening ear when things get too much.

If you are a carer this is an opportunity to let the practice know so that we can update our records and pass your name on to the .....Carers Centre in .....They will be in touch with you to provide details of their services and, if you are agreeable, add your name to the Carers Centre mailing list so that you receive regular useful information.

Please complete the attached sheet **only if you are a carer** and return it in the envelope provided.

We look forward to hearing from you,

Yours sincerely,

Dr .....

Dr .....



# Appendices

## MAILSHOT QUESTIONNAIRE

**A carer is an unpaid person who looks after a family member, friend or neighbour who is elderly, disabled or ill and needs help to live at home**

Please complete the following **if you have caring responsibilities OR pass it to your own carer to complete** then return it in the enclosed **freepost** envelope.

We will send you information about the support for carers which is available in your area from **THE PRINCESS ROYAL TRUST FOR CARERS**

YOUR DETAILS GP.....

Name:..... Date of Birth: .....

Address: .....

..... Post Code:.....

Telephone Number:.....

### I LOOK AFTER MY

His/Her name:.....

Their GP if different from your own:.....

You may have had contact with social services in the past year – if so, do they know that you are a carer? **Yes / No**

Does your GP know about your caring responsibilities **Yes / No**

If you would like someone from .....Carers Centre to contact you, please tick the box

I agree to the above information being shared with my GP

Signed .....

Please tick box if you do **not** wish this information to be shared with your GP

## QUESTIONNAIRE FOR ON-SITE CONTACT

**A carer is an unpaid person who looks after a family member, friend or neighbour who is elderly, disabled or ill and needs help to live at home**

If you are a carer, please complete the following and we will be pleased to tell you about your local Carers Centre and the support they offer. Your name will be added to their mailing list so that you will receive regular useful information.

YOUR DETAILS GP.....

Name:..... Date of Birth: .....

Address: .....

..... Post Code:.....

Telephone Number:.....

### I LOOK AFTER MY

His/Her name:.....

Their GP if different from your own:.....

You may have had contact with social services in the past year – if so, do they know that you are a carer? **Yes / No**

Does your GP know about your caring responsibilities **Yes / No**

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## PRESENTATION SLIDES ABOUT THE PRIMARY CARE INITIATIVE



Ensure that today's Carers are not tomorrow's patients.  
*A referral to your local Carers Centre is a prescription for support and advice*



**Focus on Carers Initiative**  
"Encourage joint working between the primary care sector and The Princess Royal Trust for Carers"



**"seven and a half minutes is not enough"**



The Government's National Strategy for Carers recognises that for many, the most important initial point of contact with any services is with the GP and Primary Care Colleagues



The Princess Royal Trust for Carers recognises that for all carers the most important issue is recognition of the role they undertake and being able to access help and support if required



The main aim of the initiative is for primary care workers to identify carers they have contact with and refer them on to the Carers Centre in their area.



# Appendices



The Princess Royal Trust  
for Carers

### Benefits to you and your staff:

- ✓ You have contact with specialists in carers' issues
- ✓ Patients use the Carers Centre for information and support, and so rely less on the health centre
- ✓ Valuable time is saved



The Princess Royal Trust  
for Carers

*'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  
for Carers

The good news is ...  
**this service is free**  
...but we need you to help  
to ensure that...



The Princess Royal Trust  
for Carers

... today's Carers are not  
tomorrow's patients.  
*A referral to your local Carers Centre is a  
prescription for support and advice*



# Notes



# Notes





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