King's Fund

Taking Action to Support Carers

A Carers Impact guide for commissioners and managers

Penny Banks
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Carers Impact

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11–13 Cavendish Square
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Introduction

This guide has been produced to help local health services, local government, voluntary and independent agencies implement the National Strategy for Carers. It is the third publication in a series produced from the work of the Carers Impact programme based at the King's Fund, which is described briefly in Appendix 1. The first publication, *The Carers Compass – Directions for Improving Support to Carers*, provides a framework which identifies all the policies and procedures which need to be in place locally to meet the outcomes carers want. The second, *Carer Support: Time for a Change of Direction?* is a short policy discussion paper which considers the reasons for the current gap between policy and practice and includes recommendations for central and local action.

This publication provides a more detailed and practical look at the action needed by all agencies, from the NHS, local government and the voluntary and independent sectors, to meet national policy and new central directives to improve support to carers. It draws lessons from work across the country on 19 Carers Impact sites, identified on the accompanying map, and poses questions for partner agencies to assess and move forward their work to support carers. The questions are geared to commissioning, (including strategic planning, contracting and monitoring), as well as managing services and improving practice. The guide aims to focus on outcomes and asks questions about the impact of local policies, procedures and services. Examples of work undertaken by the different Carers Impact sites provide practical illustrations for implementing local joint strategies.

The National Strategy for Carers

The first national strategy for carers, Caring About Carers, emphasises that all organisations involved with caring must now focus not just on the client, patient or user, but must include carers. The objective of the national strategy is to enable 'those who choose to care, and where care is wanted by another person, to do so without detriment to the carer's inclusion in society and to their health'. It aims to achieve the right balance such that '. . . policies and procedures should ensure that *both* people in a caring relationship are valued. We must not subordinate the needs and wishes of one party to those of the other.'

The strategy addresses three key elements: information for carers; support for carers in carrying out their caring responsibilities; and care for carers' own health and well-being. It highlights the role of a range of statutory bodies, including health, social services, education, housing and transport services to support carers.

The NHS is given a key role in identifying carers and helping them to maintain their health. One of the objectives set within the Government's National Priorities Guidance for health and social services is to 'provide carers with the support and services to maintain their health' and 'as a first step, ensure that systems are in place in primary care and in Social Services Authorities to identify patients and services users who are or who have carers'.

Partnership working between statutory, voluntary and community agencies is emphasised at all levels. Most importantly, carers and service users are to be partners in the development of local strategies within Health Improvement Programmes and Joint Investment Plans. Incentives to joint working are offered through a special grant to help carers take a break which is dependent on local authorities reviewing local provision with other agencies and carers.

Carer services provided by the voluntary sector are seen to offer important local neighbourhood support and work is to take place to develop national quality standards for these services.

Support for carers who wish to remain in employment and to return to work when their caring responsibilities end is a cornerstone of the strategy. This includes proposals to protect carers' pension entitlement.

Choice for carers and control of their life are outcomes sought through providing better general information about services as well as individualised information through assessments. There are also proposals for new legislation to enable local authorities to provide services direct to carers with possibilities of some kind of direct payment scheme or credit scheme in the future.

The strategy makes connections with a number of other policies in order to address the needs of parents who care for a disabled child, young carers and carers in rural areas. It thus provides a wide ranging agenda to be taken forward at a local level.

Carers

- There are an estimated 5.7 million carers in Britain who are family members, partners or friends providing unpaid support to people because of illness, disability or frailty
- 3.3 million carers are women; 2.4 million carers are men
- Carers are of all ages. A large proportion of carers are aged between 45–64. It is estimated there are between 20,000–50,000 children and young people who are caring for members of their family
- Carers are assisting people of all ages, children as well as adults. One half of all carers look after someone aged over 75
- Nearly a half of all carers are working either full or part-time

Acknowledgements

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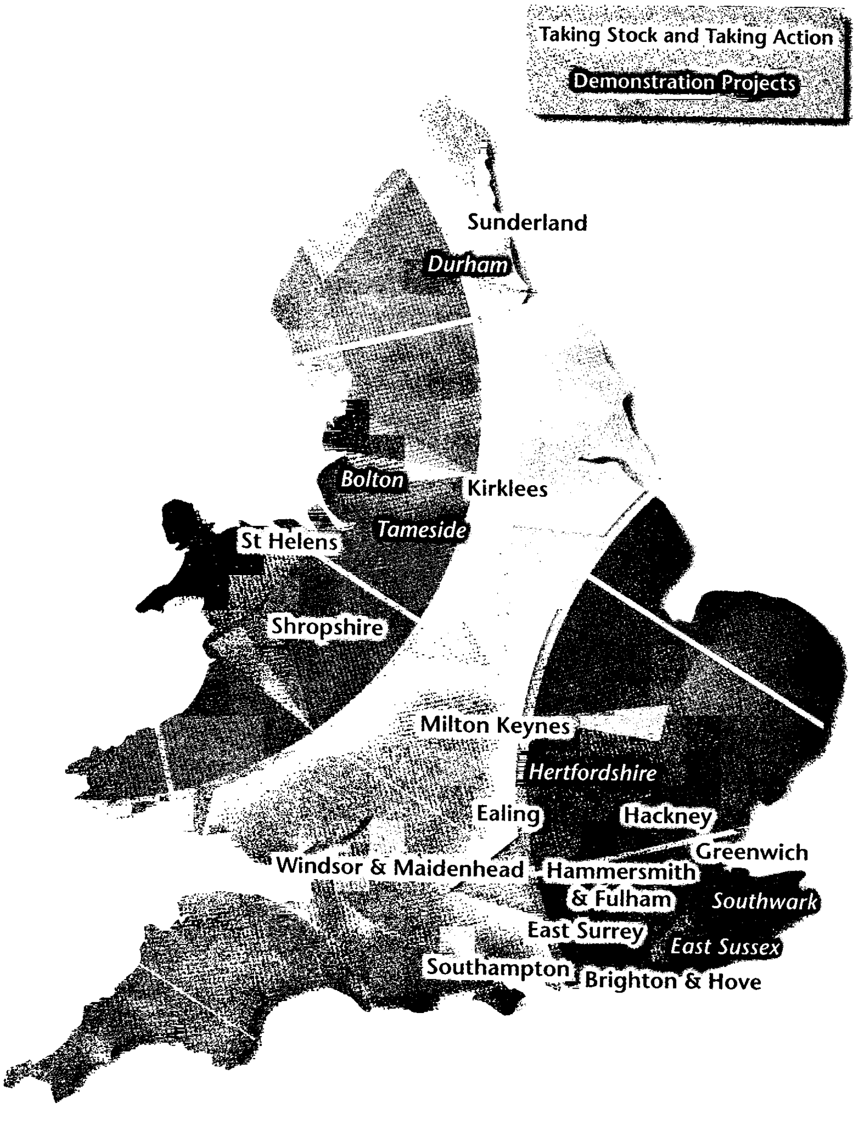
Most importantly, none of the development work would have taken place without the commitment, enthusiasm and hard work of all the people involved on the fieldsites, unfortunately too many to name individually: over 500 carers who gave their time, insight and experience, members of the planning groups, staff of all the agencies involved in progressing the work and senior officers and members who backed the programme.

The support and advice of the steering group, chaired by Rosanne Corben, has been extremely helpful, particularly in opening doors for us to a range of influential networks.

Finally, our thanks go to all our colleagues at the King's Fund, especially to Janice Robinson whose comments on endless draft papers and advice at different stages of the programme has been invaluable. Most importantly we want to thank Sarah Maggs for her major contribution to the work, particularly her inspired lay-out of reports, administration skills and endless patience.

Carers Impact was funded by the Department of Health and the Gatsby Charitable Foundation.

Carers Impact Development Sites



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Appendices:

Using this publication

Everyone concerned with commissioning and managing services in the NHS, local authorities, voluntary and private organisations can use this publication to progress their work to support carers in line with new central directives.

The guide looks in detail at each section of the Carers Compass. The Compass sets out all the policies and practices which need to be in place to support carers and to meet the eight key outcomes which carers have identified as important to them (see illustration on following page).

Questions are directed to:

- Commissioners from the partner agencies working together to plan, contract and monitor services
- Individual managers from NHS trusts, primary care, social services, education, corporate services, housing, voluntary and independent agencies who are concerned to improve front-line practice and community, domiciliary and residential services

The questions are designed to move from strategies to their implementation and delivery at the front line.

The first chapter summarises the preparatory work needed by all the agencies working together on a strategic approach to carer support and outlines essential first steps for successfully improving support to carers.

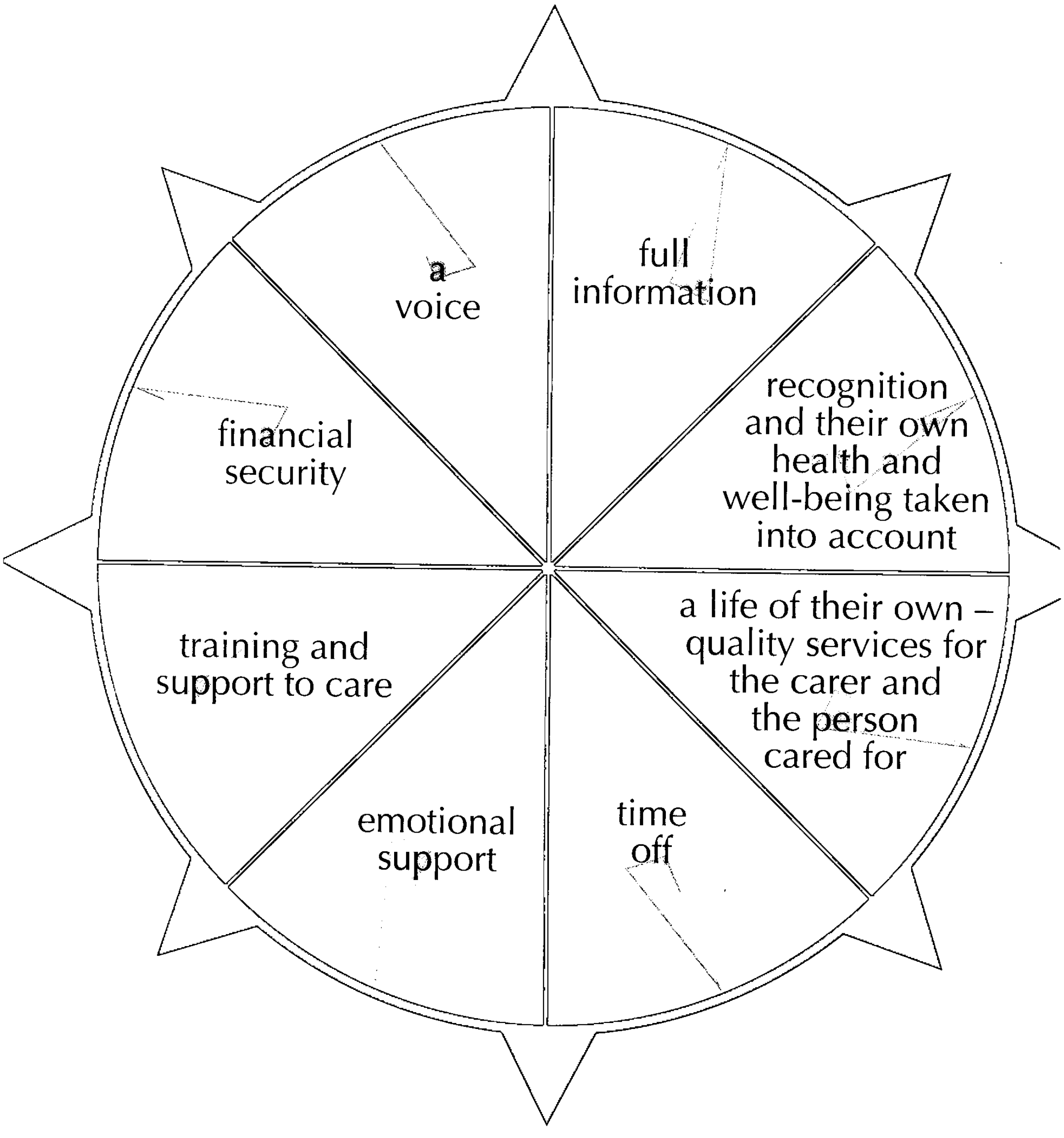
The following chapters look in detail at the practical steps which all the partner agencies need to take to achieve the eight key outcomes which carers have identified and tackles each section of the Carers Compass in turn. These chapters address the following key questions for partners:

- What are we aiming to achieve?
- Where have we got to?
- What evidence do we have about the impact of our work?
- What examples are there which can help us move forward?

Chapter 9 looks at the section of the Compass – having a voice – and discusses involving carers in every aspect of the work and ensuring services and practice are shaped by their views.

The final chapter sets out the Carers Compass for Primary Care which offers a checklist of questions for Primary Care Teams.

The Carers Compass: carers want a good quality of life for the person they care for and control of their own life. They want:



Are you heading in the right direction?

1 First steps in taking a joint approach to carer support

Being clear about carer support

Over 500 carers directly taking part in the Carers Impact programme and numerous other pieces of local, national and international research have reaffirmed what carers are seeking. Carers want a good quality of life for the person they care for and some control over their own lives. They want:

- to be fully informed
- to be recognised and have their own health and well being taken into account
- to use quality services, both for the person cared for and for themselves, which they can depend upon
- to have some time off and a break from caring
- emotional support and relief from their isolation
- training, advice and support to care
- financial security
- their voice to be heard, both in their individual situations and in the development of local services

Carers on all the Carers Impact sites described their difficulties with core health and community services, including transport, housing, education and other local services. Carers in touch with local carer groups, organisations and centres value the support they offer, but all carers speak of the importance of the response of local services, such as their health centre, general practice, hospitals and home care services; the quality of communication with professional and other staff coming into their home; and the significance of reliable services which they can trust, from whatever source. The whole service system has a part to play in supporting carers, not only the specialist services generally located within the voluntary sector.

There is evidence that many managers and practitioners from health, community and social services, do not take a broad view of carer support and are uncertain about the policy of their agency towards carers and how far they can legitimately spend time on carers' issues.

As a first step to improving support to carers, all the partner agencies from the NHS, local authorities and voluntary sector need to be clear about the role of mainstream services in supporting carers and their responsibility to recognise, respond and listen to carers.

This should be spelt out within a joint strategy for supporting carers which identifies the role of *both* specialist and mainstream services and has a clear implementation plan which details the action to be taken by each of the partner agencies and how this will be monitored.

Developing a joint strategy and action plans

The National Strategy for Carers gives considerable impetus to developing a local joint strategy or to reviewing earlier joint plans to be included within the Health Improvement Programmes. This is not about individuals writing lengthy, complex documents, but is about all the key players working together, agreeing the aims and owning the tasks to avoid duplication, maximise resources, share good practice and move the work beyond a paper exercise.

This work does need top level commitment from every agency. Experience from the Carers Impact programme shows work to support carers can easily become marginalised from the core business of the different agencies without senior officer and member backing.

Carer involvement in developing the joint strategy and monitoring the action plans is also essential to keep the focus on the carer outcomes identified at the beginning of this chapter. Chapter 9 briefly describes how Carers Impact sites developed joint strategies and action plans and some of the challenges in effectively involving carers. Appendix 3 provides a proforma for a joint strategy and implementation plan.

EXAMPLES

Senior commitment and joint strategic development

- In Tameside, progress in implementing their joint strategy is monitored by the senior joint management group. The chief executive of the local authority with directors of all the departments and the chief executive of the health authority and NHS trusts reviewed progress following the end of the Carers Impact Project and identified next steps in implementing their joint strategy.
- Elected and executive members, directors of social services and chief executives of health authorities and NHS trusts took part in a number of the Taking Stock and Taking Action workshops. This demonstrated senior commitment and gave direction and priority to the work.

Shared understanding of carers support

All the partner agencies taking part in the Taking Stock and Taking Action workshops facilitated by Carers Impact (see Appendix 1) spent time working with carers, developing a shared vision of carer support before identifying priorities for local action. This laid the foundations for their joint action plans and demonstrated the importance of a broad view of 'carer support'.

Sharing good Practice

In Hertfordshire the two health authorities and all the NHS trusts across the county met to share their current work to support carers and exchange good practice. This has resulted in plans for a countywide approach for all the community health services to signpost carers to information and help from the carers centre by using a Carers Contact Card

Working together and taking a strategic approach

Processes for co-ordinating activities across agencies and for taking a strategic approach need to be agreed. Experience suggests that leaving carers' issues to be addressed solely by client-based planning groups or carer support projects results in a piecemeal approach.

A *multi-agency planning group, with carer involvement*, which focuses on carers' issues has proved to be a successful mechanism for progressing joint work. This is not to ignore the challenges in working together which include:

- the scope of the agenda and agreeing a realistic, timetabled action plan
- the number of potential partners, particularly in large authorities
- constant changes in personnel, often due to reorganisations, either externally or internally driven
- difficulties for managers where carers' issues are only one part of a very wide brief
- obtaining wider ownership of the work, across agencies and within each organisation

Experience from the Carers Impact sites shows it is very important for the multi-agency group to have:

- clear authority from the board of each participating organisation
- explicit links to other planning and commissioning groups, including Primary Care Groups and work on Health Improvement Programmes and Joint Investment Plans
- an agreed brief for the group, including detailed action plans spelling out priorities, timescales, objectives and monitoring responsibilities
- clear roles and responsibilities for every member of the group, including carers
- an ongoing responsibility for each agency to inform and engage other practitioners and staff in the work through regular briefings, newsletters or bulletins
- mechanisms for involving carers and keeping them informed of the work
- a commitment to regularly review progress on the action taken and to monitor the overall strategy
- consistent and effective chairing
- support to the working of the group and to progress chase outside of meetings
- support to carers taking part (see Chapter 9)

Multi-agency group devoted to carers

- Bolton is to continue with the multi-agency planning group devoted to carers' issues which had been set up for the Carers Impact project, as this has been able to co-ordinate activity and make a greater impact than Bolton's original approach which expected each care group to address carers' issues. Previously, responsibility for carers had purposefully been placed within every planning group to ensure carers were part of mainstream activity. In practice, carers' issues were not always being fully addressed and the focus remained almost solely on users within each of the different planning groups.
- All of the sites in the Taking Stock and Taking Action programme who established multi-agency planning groups following the workshop found this helped them to address some of the more complex boundary issues and progress the work more effectively.

EXAMPLES

Engaging with other practitioners and staff

- The Bolton Carers Support Project produces a quarterly bulletin for staff – *Professionals Working with Carers* – which raises carer awareness, informs staff of local services, policies and research and promotes good practice.
- St Helens Carers Project produces a quarterly newsletter for carers and agencies and has regular features in local free newspapers.
- Some of the Carers Impact sites undertook a staff survey within social services, the health authority and NHS trusts to raise awareness and to get a 'snapshot' of staff's knowledge of local policy to support carers. This exercise was followed up with information to practitioners and staff and is to be repeated regularly.

Involving carers

Tameside set up a new Carers Joint Strategy Sub Group to provide a focus on carers' issues throughout local care groups and to act as a mechanism for co-ordinating the different developments across the agencies. This sub-group reports to the overall joint planning and commissioning group and includes representatives from the new Carers Council. This Carers Council has two-way communication with carers taking part in over 10 neighbourhood support groups and a direct voice into the Joint Strategy Group. This creates a network as well as clear channels of communication for carers, both between themselves and into the planning processes at every level, and they are fully supported in their work on the sub group which is implementing and monitoring the carers' strategy.

2 Ensuring carers are fully informed

> *"Trying to find information is like getting through an impenetrable web; once through you can be swamped by all the written information."*
>
> *"It seems everything I found out was by luck . . . "*
>
> *"If you don't ask, nobody tells you."*

Providing good information at the right time remains a key challenge. Carers on every site, even where there had been considerable work to produce written information, highlighted their frustration and difficulties in getting information. Many carers did not know where to start, whom to approach and often what questions to ask. There is no quick-fix solution given the large number of potential access points to services, even where there are carer centres or other one-stop shops. It does, however, underline the importance of a joint approach to addressing the information needs of carers.

What are we aiming to achieve?

Carers say they are better informed and in more control of their situation where:

- Information and advice is offered on a one-to-one basis.
- Staff from all agencies take a pro-active approach to information giving.

Carers want accurate, appropriately timed and accessible information.
They need information about:

- The illness or condition of the person they care for
  - what they can expect to happen
  - what the particular care needs of the person are likely to be
  - how they can best care for the person
- What services and support are available
  - from the NHS, social services and all other local authority services, community and voluntary groups and the independent sector to provide practical help, opportunities for a break, emotional support, training to care, financial advice
  - who is eligible for which services
  - any charges for services
  - how to obtain an assessment
  - how to gain access to help
  - what to do in an emergency

EXAMPLES

Taking information out to communities

Bilingual workers were employed to go out into the local Asian community to literally 'knock on doors' and to identify carers and invite them to a group meeting to find out their information and other needs. Further meetings followed the initial group session to provide the information which Asian carers said they needed about services and access to help. Bilingual contact points for information are also offered on an ongoing basis. *(Tameside)*

Raising public awareness

- The City Council put their posters on the length of the outside of buses publicising their new Carers Support Line service *(Southampton)*
- Questions about carers were included within a borough-wide survey undertaken by the corporate planning section which raised public awareness as well as provided useful planning material *(Tameside)*
- Carer information leaflets are to be distributed with every council tax letter going to all households in the Borough *(Ealing and St Helens)*
- Information posters about the local Carers' Centre are displayed in wards and outpatients departments in local hospitals and GP surgeries. Posters are also to be displayed in post offices, chemists and libraries along with new signposting leaflets *(Brighton and Hove)*

Information for primary care

Information resource packs for GPs and primary care teams were developed by the countywide carers organisation with carers and supported by the health authorities and social services. The pack provides facts about carers, information about local services and key action points for primary care. The impact of the packs is being monitored by carers, who are checking surgery displays and the practice's response to carers. *(Hertfordshire)*

Carers register

A carers register has been established within social services to provide a two-way exchange of information. This has led to the production of a quarterly newspaper – *The Carers Echo* – which is widely distributed to carers and professionals across the county. A designated worker updates the register and produces the newspaper. *(Co Durham)*

Carers involvement in developing information

A new Carers' Centre has been opened as a result of partnership working between carers, voluntary organisations, health services, the local authority and the Princess Royal Trust for Carers. Carers are taking part in new work to develop public information, to identify any gaps in current information provision across all local agencies, particularly GPs and primary care, and to take information out to hidden carers *(Hammersmith and Fulham)*

Where have we got to?

Questions about commissioning

A joint information strategy

- Have all the partner agencies worked together with carers to agree a joint information strategy? Does this strategy include:
  - ensuring systems are in place in primary care to provide carers with information on the health status and medication of the person they are caring for (see Carers Compass for Primary Care Chapter 10)
  - plans to raise awareness in local communities so people can identify themselves as carers and obtain help
  - a training strategy, including induction training, to ensure all practitioners and staff know of their responsibility to provide and signpost carers to information
  - a dissemination strategy for all written, visual and audio information
  - plans to take information out to different communities
  - agreed standards for the quality of information, so it is provided in a range of formats and languages accessible to *all* carers
  - plans to co-ordinate information services (such as local helplines) and set up one-stop shops if appropriate
- What arrangements are in place to ensure managers, practitioners and staff are aware of this strategy?
- What evidence do you have of the effectiveness of your information strategy?

Local support services providing information, advice and advocacy

- Are carer organisations, groups, centres or carer support workers funded to provide specialist information, advice and advocacy for carers of all ages from all communities? Has long term funding been identified?
- What plans have been agreed (prior to the establishment of national standards) to evaluate these services? For example, has there been feedback on the quality of the information provided and have the numbers and ethnicity of local people in contact with the carer organisation been identified?

EXAMPLES

- The use of checklists for people carrying out assessments is being monitored through case record audits and supervision. These checklists include a reminder about information-giving. (*Hertfordshire and Bolton Social Services*)

- Carers are involved in the audit of hospital discharge procedures through satisfaction questionnaires and are checking to see if all carers are given adequate information. (*Royal Bolton Hospitals NHS Trust*)

- A named 'carers contact' has been nominated in surgeries to check information is provided to carers; this may be given by a receptionist, practice manager or practice nurse. A specialist carer outreach worker supports these staff within about six different practices. Each practice agrees a clear brief for the outreach worker who keeps the practice provided with up-to-date information and arranges carer awareness training for all practice staff. (*East Sussex*)

- Every care plan given out to patients and their carers by nursing and other community health staff includes a Carers Contact Card which directs carers to the local carers organisation providing information and advice. (*East Hertfordshire NHS Trust*)

- The pharmacy department of an NHS trust in consultation with carers has produced a Carer's Guide on Using Medicines which provides easy-to-follow advice on common problems in giving medication and how community pharmacists and nurses can help. (*Optimum Health Services NHS Trust, Southwark)*

- An audit is being undertaken to evaluate the effectiveness of a Carer's Pocket Guide. This is a laminated card distributed to all the community nurses which fits into their diary/filofax and highlights the information carers need and advertises the local lifeline. This was produced in partnership between the voluntary organisation, Care for the Carers, the community NHS trust and Eastbourne Borough Council. (*East Sussex*)

- Southampton Carers' Association, carers, health and social services have worked together to review all local information and to develop a special signposting pack for new carers and for professionals. This will be kept updated and reviewed by the Carers' Association. (*Southampton*)

Questions about managing services

Carer-awareness and giving information one-to-one

- What arrangements are in place to check that all practitioners and staff are carer-aware and they know the importance of being proactive in identifying carers and asking carers about their needs?

  Example: line managers' supervision responsibilities include checking that staff are following procedures for identifying and working with carers

- Do induction and training programmes include carer awareness and are carers involved in delivering the training?

- What checks are made to ensure practitioners routinely ask carers if they have the information they need to care?

  Example: audit of checklists within records/files

Updating information

- How is information relating to carers kept up to date and provided to practitioners?

  Example: nominated member of team/unit/surgery with responsibility to update information

Information-giving at critical times

- Has responsibility for information-giving at critical times, such as at hospital discharge, visits to the GP and at the time of carers' assessments, been clearly assigned?

  Example: manager/practitioner given clear responsibility to check who/how/when information is given out

Sensitive information-giving at the time of diagnosis

- Is there a policy or guidelines on sensitive information-giving at the time of the diagnosis?

- What arrangements have been made to carry out self-audits of practice? See Walker *et al* 1997, *Breaking Bad News*, Appendix 4

- How are carers consulted about their experiences at the time of diagnosis?

Quality of information

- How is regular feedback obtained from carers on the quality of information-giving and the quality of written information? For example:
  - carers are involved in the development of any new information material
  - carer groups are consulted regularly
  - a readers panel of lay people reads all public information drafts

3 Recognising and assessing carers' needs

"There's nobody there for me. Nobody asks how you are coping."

Carers say they are frequently 'ignored and invisible' in their dealings with services whose focus is on the patient or user of services (Henwood 1998). It is generally assumed partners or relatives will take on a wide range of nursing and caring tasks. At the same time, the expertise and experience of carers can be dismissed or overlooked by professionals. Carers' own needs for a break or other support are given little attention. This leaves carers isolated and unable to obtain help until there is a crisis and their own health, emotional and physical, breaks down, forcing services to respond. Some professionals are sensitive and responsive to the needs of carers but there is no consistency in how the GP, the community nurse, the social worker, the housing manager or other paid staff recognises or responds to the carer.

The *Carers (Recognition and Services) Act 1995* gives carers an entitlement, on request, to an assessment when a local authority carries out an assessment of the person cared for. The Act covers adults, children and young people and parents of disabled children, who provide or intend to provide a substantial amount of care on a regular basis. Guidance from the Department of Health (Practice Guide 1996) underlines the importance of a shift in practice towards:

- greater recognition of carers, paying attention to and taking account of what they say
- an assessment of the 'caring system' which considers the range of support available to service users and carers
- an integrated family-based approach which does not see either the user or carer in isolation
- an opportunity for a private conversation without an elaborate procedure and where carers are not having to repeatedly provide the same information

Whilst the Carers Act has given carers an entitlement to an assessment of their needs by local authorities, the evidence from the recent SSI inspection of local authority support for carers (Department of Health 1998) and feedback from carers on the Carers Impact sites show assessments and reviews for carers are not yet routinely part of social services practice. Many carers are unclear about their entitlement under law or in line with local policies and procedures. Staff also appear to be unclear both about carers' entitlement to assessment and the benefits of assessment where there are budget restraints.

What are we aiming to achieve?

Carers say there are a number of positive outcomes for them in having an assessment even where practical services may be restricted because of financial constraints. They value:

- recognition of their role
- peace of mind from knowing how to make contact in the future
- a chance to talk through the issues and consider their own needs
- information which can be provided on other support, such as carer groups and local statutory and voluntary services
- a sense of shared responsibility, particularly where any support offered is on a regular basis
- increased confidence to take up services

Carers need information about the benefits of an assessment, what is involved and how they obtain one. They should always be clear when an assessment is being carried out and given written evidence of the assessment and planned allocation of services. Carers should also be told why decisions have been made and if there are any charges for services.

Health services role in assessments

Health professionals have an important part to play and are well placed to notice signs of stress or any deterioration in the health of carers and to identify young carers.

They can alert carers to their right to request an assessment under the Carers Act when making a referral for a user's assessment and can encourage carers to take up the opportunity for an assessment by explaining the benefits, as identified above.

GPs, nurses, therapists and other health professionals can also contribute their experience towards the holistic assessment of a carer's ability to provide and to continue to provide care.

Housing authorities and assessments

Housing authorities may need to 'assess the carer's circumstances, wishes and needs in the provision of accommodation which is right for him or her and for the person needing care' (National Strategy for Carers 1999).

Education and assessments

Schools are in a key position to recognise young carers and to link with the education welfare service, social services and young carer projects.

EXAMPLES

Recognition by Hospitals

Homerton Hospital NHS Trust is testing out its new policy to recognise and support carers. Carer awareness training for nurses is taking place and questions about carers are included on hospital forms which have to be completed within 48 hours of admission. A new post has been created to support carers at discharge and to liaise with community services and the local carers' centre. (*Homerton Hospital NHS Trust, Hackney*)

Recognition by Primary Care

- An 'award scheme' for general practices investing in carers was set up to encourage practices within the borough to develop their work with carers and to visibly express their support through carer noticeboards displayed in each practice and clinic. Also, a bid for work with GPs is being submitted as part of a local urban regeneration scheme. (*Tameside*)
- Greenwich has a joint strategy to align adult carers' support to Primary Care Teams in keeping with other local developments to jointly develop services for older people. Local carers' organisations are being commissioned to provide Primary Care Aligned Carers Support Workers to work alongside other professionals within the primary care setting. One of the other key goals for the strategy is to ensure all relevant professionals 'think carer', so the new support workers are not expected to be carrying forward the carer agenda alone. (*Greenwich*)
- A carers linkworker has been appointed to work with Primary Healthcare Teams to raise carer awareness to support PHCTs to implement practical initiatives for carers and to produce information for carers. Surgeries are shown ways of identifying carers through flowcharts, carers audit and tagging records. Carer support issues are being written into practice development plans. (*Bolton and Kirklees*)
- The Community Trust has just employed a health visitor with a specific remit on elderly people and carers. The health visitor visits carers in their homes to provide support and to link carers to other services. The health visitor has helped to compile a register of carers at the general practice and to tag records. (*Milton Keynes Community NHS Trust*)

Recognition by Housing

Carers' issues are included within the local housing allocations policy which aims to help carers live near the person they care for. Carer awareness is within the induction training of sheltered housing wardens and they are kept updated on issues through a special bulletin produced for professionals by the Carer Support Project. (*Bolton*)

Transport and Carers

Carer groups and voluntary organisations have been consulted as part of the development of an integrated transport policy. (*Royal Borough of Windsor and Maidenhead*)

Where have we got to?

Questions about commissioning

Local joint strategies and plans

- Does the Heath Improvement Programme include a joint strategy on recognising and supporting carers which addresses the National Strategy for Carers and meets National Priorities Guidance?
- What plans do Primary Care Groups have to address the needs of carers? (See *Carers Compass for Primary Care* chapter 10)
- How effective are local discharge planning procedures in involving carers and ensuring carers know about their rights to an assessment under the Carers (Recognition and Services) Act 1995?
- Is support to carers on the corporate agenda and what are departments other than social services doing to recognise carers particularly housing, transport, education and personnel?
- What plans do other community services and the business sector have to recognise carers?
- Is there a multi-agency young carers strategy which links with the Children's Services Plan, the Community Care Plan and the Health Improvement Programme?
- What arrangements are in place to ensure managers, practitioners and staff, including those working within residential and nursing homes, are kept updated about strategies and plans to support carers?
- How effective are local strategies and policies at recognising carers and assessing their needs? What evidence do you have?

. . . continued on page 17 . . .

Multi-agency strategy on young carers

A multi-agency strategy on young carers was developed in consultation with the County Council, District and Borough Councils, Health Authorities, NHS Trusts, carer and other voluntary organisations and a 'menu' of tasks identified for each of the agencies. All the participating agencies meet annually to monitor progress in implementing the strategy. There are plans to hold an exercise for all the different agencies to test out the strategy, develop referral tools between agencies and find more practical ways of supporting young carers once they have been identified. (*Hertfordshire*)

EXAMPLES

Joint workshops held on the Carers Impact demonstration sites between health and social services managers, staff carrying out assessments and carers were useful to:

- Review local practice to see where and why local policy was not being put into practice
- Clarify policy and procedures
- Agree standards
- Develop checklists of good practice
- Identify monitoring systems.

Examples from the workshops on Good Practice Standards in Carer Assessments

1: Every professional, from all agencies, has a responsibility to identify the existence of an actual or potential carer in each situation.

2: Clear information about assessment, in a range of formats, is made available to carers.

3: Before the assessment meeting carers are given information about what will happen, who will be involved, where they would prefer the assessment to take place and when and who to contact if problems arise in the meantime.

4: It is made clear to carers at the beginning of the assessment meeting what will happen, who it is for, and what will happen next.

5: Assessments give carers confidence and treat carers as equal partners, by assessors listening carefully, making no assumptions, being non-judgemental and providing honest, clear information.

6: Assessments should cover all the needs of carers – they should be holistic and multi-disciplinary where appropriate.

7: Recording is explained and shared and a copy of the assessment is provided for the carer.

8: The assessment is followed up to ensure the carer knows what is happening and the care plan clarifies which agencies and caring networks will meet the assessed needs and how they will be co-ordinated.

9: Carers receive a copy of the resulting care plan and details of how their needs can be reviewed.

- A joint meeting was held between county councillors, social services staff and carers to review how carer assessments were being undertaken using new local eligibility criteria. The difficulties for carers being heard and the variable practice by assessors signalled some real difficulties in interpreting the new policy and led to a review of procedures and practice. (*Hertfordshire*)

Questions about commissioning *(continued)*

Carer assessments

- Is there an explicit local policy in place about carers entitlement and eligibility to assessment under the Carers Act? Do you have an ongoing training programme to ensure staff from health, social services and the voluntary sector are clear about this policy and local procedures?
- What procedures are in place to co-ordinate assessments in complex situations and to ensure carers do not have to constantly repeat the same information?
- What systems are in place to record:
  - the number of people who have had their own assessments and who have a carer
  - the numbers of carers who have had an assessment, either separately or jointly with the service user?
- Are unmet needs recorded and collated for planning purposes?
- Is there a public information leaflet clearly explaining
  - the purpose of assessments
  - carers entitlements to assessment
  - who they should contact
  - what they might expect as a result of the assessment
- Is this information in a format and language appropriate to carers from all communities and carers with disabilities?

EXAMPLES

- The Health Authority is funding a programme of training and carer awareness raising for primary health care teams from the six primary care group areas. Joint training sessions have also been arranged for health, social services and the voluntary sector. The programme has been developed in collaboration with carers, the countywide training units and carers workers. The Carers Compass is being used within the training sessions. Each primary health care team will be encouraged to identify a key contact for carers. (*Shropshire, Telford and Wrekin Council*)

- A carer awareness raising session is included in the induction programme for all staff within the community and mental health trust. This has been planned with the carers' project worker. (*Shropshire, Telford and Wrekin Council*)

- A Young Carers Resource Pack has been disseminated to schools with information to assist teachers in identifying and supporting young carers and to increase pupils' understanding of disability, illness and caring responsibilities. The materials are designed as a half-term module of lessons to be integrated into schools' existing Personal, Social and Health Education programmes. The pack includes background information for teachers and suggestions for supporting known young carers within schools and through other agencies. The implementation of the pack was supported by a training programme for Surrey schools. The pack was produced through a collaboration between the Surrey Young Carers Project, Soroptimist International of Reigate and District, Surrey Education Service and schools. (*East Surrey*)

- Two videos have been produced with young carers. One video is to raise general awareness and the other is for teachers, primary health care teams and other children in school, with an accompanying information pack. (*Hertfordshire*)

- To improve the quality of assessments, Tameside Social Services has recruited and trained sessionally paid staff to support community care assessments by providing language skills, culturally specific information and advice to assessors on possible 'solutions'. This service has helped carers by relieving family members of the role of ensuring people understand what is being said and has helped women carers to be more fully involved. (*Tameside*)

- A group of carers and practitioners has been set up to review the assessment process and to make recommendations to change practice and the documentation. (*St Helens and Southampton*)

- As a pilot scheme, a member of one social services team has been nominated as a 'carers champion'. This person co-ordinates information about carers issues, helps raise carer awareness of colleagues and advises on carer assessments as well as undertaking some separate carer assessments. (*Bolton*)

Questions about managing services

Identifying carers and their needs

- What arrangements are in place to check whether all practitioners and staff are carer aware and pro-active in identifying carers and asking about the needs of carers, including their health needs? *For example:*
  - *audit of completion of checklists by frontline staff*
  - *supervision*
  - *spot checks on case files*
  - *review induction records*
- What arrangements are in place to check whether staff within residential and nursing homes are aware of the needs of carers and are working with them as partners?

Carer assessments

- What arrangements are in place to ensure all practitioners know about carers' entitlements to assessment under the Carers Act, understand the importance of assessments and know how carers can get their needs assessed locally?

  Example: regular joint training sessions with carers involved
- What arrangements are there to check the quality of assessment practice by practitioners?

  Example: do all carers know an assessment has taken place?
- Has the use of assessment forms and self-assessment forms been reviewed?

  Example: Review of case records; Supervision

  (See Appendix 2: Checklist for frontline and reception staff and practitioners carrying out assessments)
- Are the number of carer assessments being recorded?
- What arrangements are there to check assessments are followed up and carers are kept informed about the outcome of assessments?
- What systems are in place to obtain regular feedback from carers about their experiences of being recognised and/or their needs assessed?

  Example: regular visits by managers to a small sample of carers

4 Quality services

> *"Five different care workers came in one week – I never knew who was coming in and every time I had to go through what needed to be done and show them how to do it . . . "*

> *"I was so worried that there were not enough staff to help him eat his meals, I used to go up to the hospital twice a day to make sure he had had something to eat . . . "*

> *"I was offered help with bathing my husband but what I really needed was someone to help with the cleaning and take the heavy bins out . . . "*

> *"Unpredictable and inappropriate services, or services granted and then withdrawn, were seen as a source of extra strain rather than a means of relief." (Carers Impact Report on the feedback from carers – Unell and Bagshaw)*

> *"It is essential that carers using any form of service – whether provided by the statutory or voluntary sector – should have confidence in the quality of that service." National Strategy for Carers*

Carers say they are best supported where services, either for themselves or for the person they care for, are of a quality that gives them peace of mind and are adaptable to suit both their needs. Most importantly they want continuity of staff who are competent and work closely and sensitively with both the carer and person cared for.

Carers also want to ensure above all else that the person they care for has a good quality of life. Inappropriate day care and poor experiences of residential or health services leave carers caught between the desperate need for a break and the guilt of seeing their relative, partner or friend inadequately cared for by someone else.

What are we aiming to achieve?

Health and social services, housing and all community services, statutory, voluntary and independent, need to address the following carer quality standards:

- **Fair access:** so there is visibly fair and equitable access to services and clarity about who is eligible for what.
- **Sensitivity:** where there is sensitivity to all the interests involved in each situation; no assumptions are made about the needs of either the carer or the person cared for; and agreements are carefully negotiated between the user and carer and the services.
- **Confidence:** so that services give confidence to the carer and can be trusted, in the way the services are delivered, their consistency and reliability, and the expertise and competency of the staff.
- **Shared responsibility:** where carers feel the services share responsibility and do make a positive difference in their appropriateness and flexibility to suit individual needs and circumstances.
- **Emergencies:** where services effectively and promptly respond to emergencies and carers know whom to contact to get help in a crisis.

Monitoring the quality of services

Different ways of obtaining systematic feedback on the quality of services is illustrated in the examples from the work on the different Carers Impact sites. Other ways of obtaining feedback are discussed in Chapter 9.

Whilst all the agencies on the different sites have adopted policies which welcome both comments and complaints, many carers speaking to the Carers Impact researchers expressed their fears of making any kind of complaint or negative comment in case the person they cared for was victimised in some way or they would lose the services they relied on. The very real difficulties for carers in using any kind of complaints procedure cannot be underestimated.

EXAMPLES

Developing and monitoring standards

- Carers are taking part in a panel with users, set up by the Social Services Department, to develop and monitor standards for homecare. They have been involved in the process of awarding a block contract by conducting interviews and asking homecare agencies what they would do in situations that test criteria the panel considered important. These include good communication with the agency, continuity, punctuality and competency of homecarers. (*Hertfordshire*)
- In response to feedback from carers new specifications were included in the local authority contracts for homecare; these included performance targets for maximising the consistency of workers and informing carers. These standards are being monitored through spot checks, practice audits and obtaining feedback from carers. (*Southwark*)
- Carers have been involved in developing the quality of the local continence services, working together with the health authority on criteria for accessing the service and publicity to carers. Carers will continue to be involved in monitoring feedback and any complaints about the service. (*Tameside*)

- The NHS Trust have incorporated carers' issues into their annual service plan and objectives. An audit of carers' experience locally is being undertaken to check if staff are proactive in asking carers about their needs and whether carers are offered access to assessments and benefits advice. (*Optimum Health Services NHS Trust, Southwark*)

- Homecare services run by black voluntary sector organisations are being supported by the local authority to provide appropriate, culturally sensitive services to black carers. (*Southwark*)

- A 'Care Passport' is being piloted in the Eastbourne Hospitals Trust, working with the voluntary organisation, Care for the Carers. This is a card providing details about any special needs of the patient with notes completed by the carer. This card is put by the patient's bed in hospital for use by all staff to provide easy access to carer's knowledge in assisting with the cared-for person's daily needs and to give carers 'peace of mind'. (*East Sussex*)

- All district nursing notes are held by the patient and family and some accompany patients going into hospital. Carers can add information to the notes and this gives them confidence that hospital and other staff are fully informed about the individual needs of the person cared for. (*East Hertfordshire NHS Trust*)

- Carers have been working with the community and acute NHS trusts to improve the quality of hospital discharge. Standards have been agreed about a core set of information to be provided and the engagement of carers in the process. The Carers' Centre is to audit the information giving. Regular working practice audits will monitor practitioners' involvement of carers. (*Tameside*)

Where have we got to?

Questions about commissioning and managing services

- How are you involving carers in developing quality standards for local services, statutory and voluntary, in order to meet the outcomes carers want?
- Are you including equality issues within these standards so that the needs of carers from all communities are addressed?
- What arrangements have been made to inform individual carers and the public of the standards agreed for local services?
- How are managers, practitioners and staff made aware of these standards?
- Have the quality standards been translated into specific service features which can be monitored? (See, for example, *Listening to Users of Domiciliary Care Services Developing and Monitoring Quality Standards* Henwood, Lewis, Waddington Nuffield Institute for Health 1998)
- Do all service specifications and service level agreements include carer standards?
- How are you involving carers in monitoring and evaluating the effectiveness of these standards?

EXAMPLES

Responding to emergencies

- A Carers Emergency Card, developed by carers, provides carers with reassurance in case of an illness or accident. No personal details are on the card but information about alternative care, their GP, the needs of the person cared for and key holder contacts are kept by the 24-hour emergency line run by the district council. The carers organisation, Care for the Carers, deals with applications for the card and monitors the scheme. (*East Sussex*)

- Social services works with the Red Cross to provide an emergency card scheme for carers. The Red Cross 24-hour line contacts substitute help for carers and where this is not available provides emergency volunteer back-up services. (*Durham*)

- City Health and Housing Services have extended their community care alarm service to people with mental health problems and community care staff have received training to ensure an appropriate response to service users and carers. (*Sunderland*)

5 Opportunities for a break

> *"It keeps me sane. Without a complete break, it would be very hard to cope. I would have nothing to look forward to."*
>
> *"The help I get enables me to stand back, get my breath and feel refreshed so I can start again."*
>
> *"The rigidity and sameness of the daily routine got many carers down, and some admitted to frustration with the person cared for. Incontinence, night-time waking and incessant repetition were particular sources of strain . . . " (Carers Impact report on feedback from carers – Unell and Bagshaw)*
>
> *"The constant and unremitting responsibility for another person, with its associated feelings of tiredness, resentment and frustration, engendered considerable stress. To this were added financial pressures in many cases and the frustration of trying to keep up with the routine chores and commitments of daily life. There was often, too, an underlying sense of sadness at seeing the cared-for person deteriorate or observing the increasing gap between a child's development and that of other children . . . " (Unell and Bagshaw)*

Opportunities for a break rate amongst carers' highest priorities. The type of break which individuals want covers a very wide spectrum. It ranges from regular sitting services during the day or day opportunities for the person cared for; to someone coming in overnight to give carers a night's sleep; to live-in care arrangements or residential provision whilst the carer has a holiday; to holidays taken together by the carer and cared-for person. A sensitive assessment of each situation where the needs of both carer and user are considered together and where breaks are seen as part of a whole package and programme of support is a prerequisite for providing an effective service tailored to the individual.

From the evidence of the Carers Impact programme, a joint approach is crucial in addressing opportunities for a break in order to address a number of boundary issues and maximise resources. Those authorities who tackled this alone ended up making very little progress.

What are we aiming to achieve?

Carers and the person cared for need:

- easily accessible information about a range of opportunities for a break which offer time for themselves and give carers a rest from caring;
- as much control as possible as to where, when and how they take a break;
- flexible, responsive and reliable services which can be tailored to both of their needs. These will include:
  - services that can offer a break from their normal routine, either separately or together if preferred
  - services in their own homes or in a variety of other locations, ranging from family homes, day centres, care homes, hospitals, rehabilitation centres to hotels
  - services offered at times most convenient to the user and carer which may include out-of-work hours, at very short notice and for varying durations
  - services which can respond in emergencies
  - assurance that the short-term care provides a positive experience for both the user and carer
  - breaks which are part of an integrated, reviewed, programme of support tailored to each individual situation

References

A Real Break: Guidebook on the provision of short-term breaks
published in association with the National Strategy for Carers. February 1999

Promoting Independence: Partnership, Prevention and Carers Grants – Conditions and Allocations 1999/2000
Local Authority Circular LAC(99)13

EXAMPLES

- A number of sites have begun joint work between the health authorities, social services, the voluntary sector and carers to agree a joint strategy which includes:
  - achieving a shared understanding about opportunities for a break
  - mapping current services which offer a break across all the sectors
  - identifying needs by collating local information on the use of services which offer a break and unmet needs recorded from assessments
  - working with users and carers to draw up a specification for the 'ideal' service which offers a break.

- Carers and voluntary organisations are being consulted about opportunities for a break to inform a new county respite strategy. Several pilot schemes have been set up with small amounts of funding to develop existing services, including, for example, transport provision, and to find more creative solutions for individuals who have been unable to find the appropriate service offering a break. These pilots are to be evaluated and the lessons will be used to develop the county respite strategy. (*East Sussex*)

- The need for more opportunities for a break for carers of people with mental health problems was highlighted within the two-day Taking Stock and Taking Action workshop. Resulting service initiatives include the appointment of six community workers to support people in the community and short term accommodation for people with mental health problems. Carers have continued to meet and this group has two fixed sessions a year with senior officers to monitor progress. (*Sunderland*)

- Social Services and the Health Authority have worked together to use Challenge Fund monies to support carers in ways which carers have identified as helpful to them. This has resulted in a number of events, often purely recreational, to give carers a good break. (*Royal Borough of Windsor and Maidenhead and Berkshire Health Authority*).

- As part of the Best Value review of learning disability services, there has been wide consultation and questionnaires to find out the views of both carers and individual clients. This has resulted in opening a day service on Saturday. (*Royal Borough of Windsor and Maidenhead*)

Where have we got to?

Questions about commissioning

A joint strategy

- How are users and carers being involved in developing a joint strategy to provide a break? Are carers from all communities being involved?
- Does the joint strategy:
  - have a clear, shared vision about short-term breaks
  - offer a range of options, including breaks in people's own homes as well as away, either separately or together
  - offer services which are sensitive to different cultural and ethnic minority needs
  - address the needs of young carers
  - include ordinary activity-based schemes and holiday schemes
  - specify carers and users entitlements to services offering a break
  - give as much control as possible to users and carers as to where, when and how they have a break
- Has it been agreed which services might be best jointly commissioned and how this will be organised and funded?
- What arrangements are in place to record unmet need and service shortfall for planning purposes, including gaps in services for particular groups of people (for example, people with Alzheimer's Disease?)
- What arrangements are in place for monitoring and evaluating the quality of local services which offer a break? Does this include monitoring the reliability and consistency of services and whether staff have appropriate and adequate training?
- What arrangements are in place to ensure managers, practitioners and staff are fully briefed on the joint strategy?
- Overall, how effective is this strategy? What evidence do you have?

Informing Carers

- Is information made available to the public about the services which offer a break and who is entitled to what? How do you know if this is reaching carers from all communities and carers with different caring responsibilities?
- Are the charges for any short-term breaks consistent and clear and has this information been made available to users and carers? How are you assessing the effectiveness of these charges and the impact of these on the uptake of services?

EXAMPLES

- Carer assessments are to be audited to ensure assessors ask about breaks and to identify whether and why carers have ever decided not to use a service offered. (*Hertfordshire*)

- A requirement within the local contract with Crossroads that a carers assessment must have been carried out before a service is provided has not only helped to target those in most need but has also improved the quality of overall packages of care. The assessment has ensured that other support needs, both immediate and longer term, have been considered. (*Bolton*)

- A CarersNet website on the internet is being set up which will provide information about carers support and opportunities to take a break. (*East Surrey*)

- Crossroads Playbase provides a safe play environment for children with special needs on Saturday mornings and enables their parent carers to take a break. (*Brighton and Hove*)

- Service developments to offer more flexible respite care in response to carers feedback include:
    - A respite care voucher scheme for older people and their carers, who can choose to use this if they want to arrange their own care
    - Crossroads provides a Day Stay Service offering up to 48 hours of care in the service users' home, a night sitting service and a Children's Day Centre on Saturdays to give parents with a disabled child a break
    - The British Red Cross offer an emergency care service
    - The appointment of carer support information officers for mental health services
    - Research commissioned by the health authority to review resources and plan for future need for people with learning disabilities and their carers
    - Increased Adult Placement Services for both short and longstay provision. (*Kirklees*)

Questions about managing services

- What arrangements are in place to check that practitioners and staff:
  - know about the importance of carers' and users' need for a break?
  - know about the range of options provided locally and carers' eligibility for these services or that they can signpost carers to those agencies which can provide the information?
  - carry out assessments which are sensitive to the needs of both the user/patient and carer and carefully negotiate agreements?
  - carry out assessments and offer services which are sensitive to different cultural and ethnic minority needs?
  - record the different needs of users and carers as well as those needs which cannot be met?
  - provide full information about the charging policy and costs of the different options available?
  - ensure carers are aware of any impact on their welfare benefits?
  - ensure carers have telephone or other contacts for reassurance if a separate break is organised for the user and carer?
  - ensure carers and users know how to make a complaint or feedback suggestions to improve the service offered?

6 Emotional support

> *"We were on our own. We knew nothing and we had no reason to know."*
>
> *"Where the person cared for suffered from mental health problems, the carer seemed to be riding a roller-coaster of demands, with peaks of stressful, all-consuming care followed by periods of tranquillity. The unpredictability of this pattern was in itself a source of great anxiety for the carer." (Carers Impact report, Unell and Bagshaw)*
>
> *"For some carers, the hardest thing was the loss of spontaneity and independence in their own lives and the consequent combination of feeling socially isolated but having no personal space within the home. This was neatly summed up by one man who said: It's being unable to do anything independently and no life of my own. Wherever I go I have to take my wife." (Carers Impact report, Unell and Bagshaw)*

The positive aspects of caring and what gets carers down will obviously vary from one individual to the next and is likely to reflect what people see as either new or missed opportunities and the quality of the relationship between the carer and person cared for. Although each situation is unique, the isolation of caring and the need for some kind of emotional support are universal experiences.

What are we aiming to achieve?

Given the uniqueness of each situation there is inevitably a broad spectrum of approaches which can support carers. These may range from sensitive and helpful responses by receptionists and other staff with whom carers first come into contact; to support from other carers, informally, in groups or by telephone; through to specialist and specific counselling offered by the NHS, voluntary and private agencies.

The timing of the response is also important: carers need access to prompt help, often outside standard office hours. It is not only a speedy but also a timely response which is essential. At times of crisis, for example when a diagnosis is given to parents or relatives, a sensitive response can make a difference which has long-term benefits. Carers have said that the right words at the right time have given them confidence to take up services and support later on in their caring career and conversely a brusque and offhand response has compounded their guilt and anxiety about asking for any help. Hence, local health community services can play a crucial role in ensuring carers are sensitively supported and have the confidence to engage with services.

EXAMPLES

- All local counselling services were listed and checked to see whether they were registered with the British Counselling Association. This information is now included in the carers' information pack. (*Tameside*)

- A one-day conference was held to bring together all the agencies and services providing some kind of emotional support to carers with the aim of mapping out what is offered and to find better ways of supporting carers. (*Hertfordshire*)

- Induction training for all community NHS Trust staff includes carer awareness. A staff survey before and after the training was partly used to assess the impact of the induction training. (*East Hertfordshire NHS Trust*)

- An audit system checks if district nurses provide or arrange for emotional support to carers. As part of their ongoing responsibilities nursing managers check practice through supervision and undertake periodic visits to a small sample of their staff's patients and carers. (*Bolton Community Healthcare NHS Trust*)

- A 'Phone-out' service has proved to be more successful than the previous expensive helpline. Volunteers, who have experience of caring, have a short training session with the Samaritans and the local carers project and when they are making calls they have the support of a paid member of staff at the carer support project. The volunteers pro-actively phone carers known to the carers project. This service reaches out to carers in their own homes and provides an opportunity for carers to talk, to express any concerns and to obtain information. Follow-up action, if required, is provided through the local carers project. (*Milton Keynes*)

- Carer support nurses within Elderly Mental Health Teams support carers, provide advice on the management of symptoms of dementia, co-ordinate short breaks and provide bereavement and loss counselling. (*Royal Bolton Hospitals NHS Trust*)

- Four carers support groups across the town offer emotional support, along with the Carers Worker who is able to provide support on an individual basis. (*St Helens*)

Where have we got to?

Questions about commissioning

Local services offering emotional support

- Have you mapped out the carer networks/support groups/ centres which carers can easily access in your area? Are there any geographical gaps?
- Are there centres, groups and other local services which offer emotional support appropriate to carers:
  - of different ages
  - from different communities
  - and those caring for people with different disabilities and illnesses?
- Prior to the agreement of national standards, what outcome measures have been agreed for these support services and how are these monitored?

  Example: at least x% of the carer population has contact with the carers' centre including telephone calls, mail outs, outreach work.

Responses at first contact

- Has a protocol been set up for induction training which includes carer awareness and is it provided for all practitioners and staff, including receptionists? How is this monitored?

Questions about managing services

Listening to carers

- What arrangements are in place to audit good practice of all practitioners and staff in listening to carers and offering, or signposting to, emotional support?

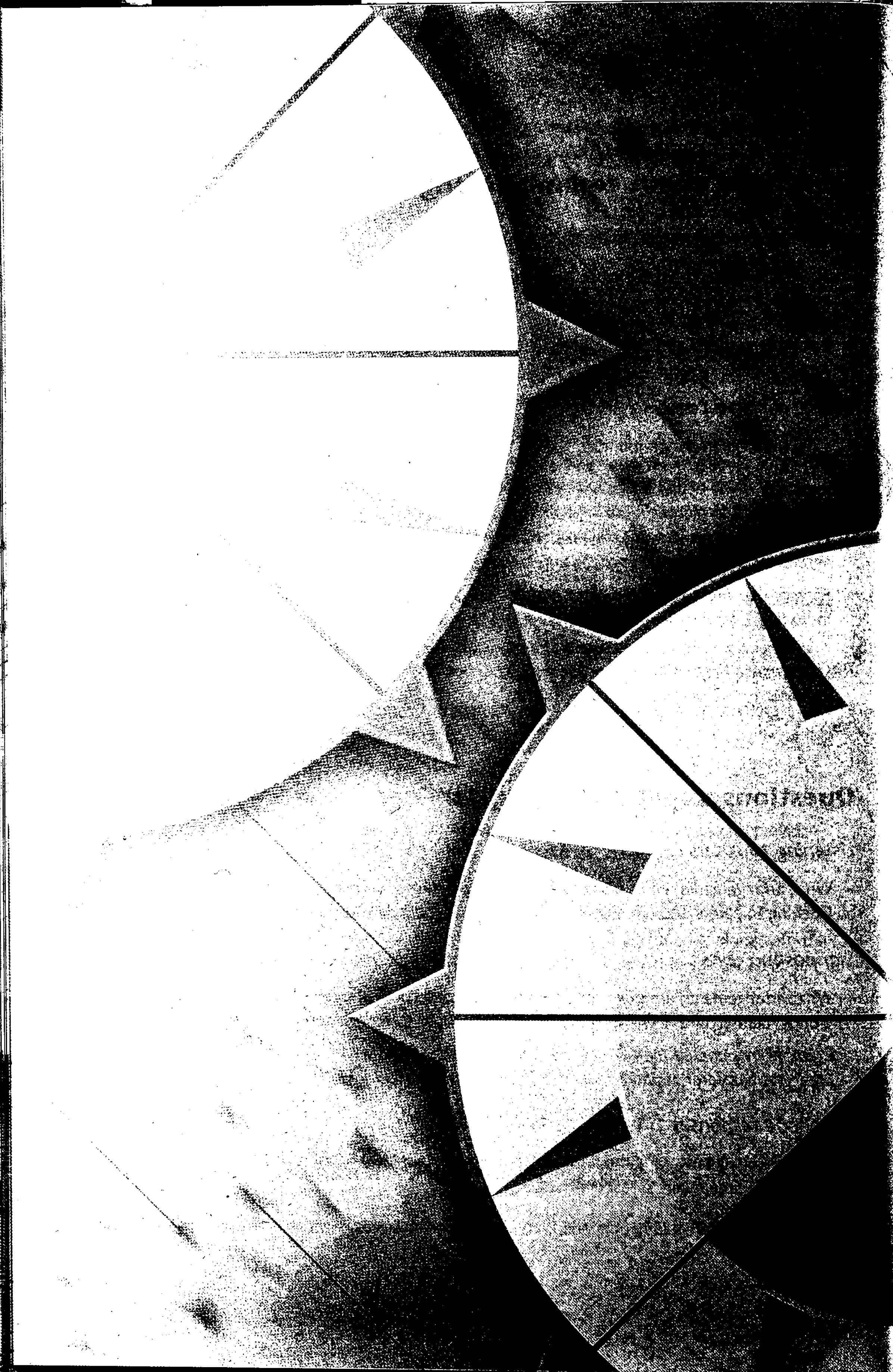
Signposting carers

- What arrangements are there to ensure all staff have updated information about carer groups, centres and networks and broadly know what these can and cannot offer?

  Example: nominated member of the team/unit/practice liaises with the carer organisations/carer support workers and keeps information updated

Telephone responses

- Are checks regularly carried out on telephone responses, how a call is answered as well as the time taken to respond?
- How is feedback regularly obtained from carers about their experiences of telephoning your office/service?



7 Training and advice to care

Carers are often expected to take on medical procedures and caring tasks with inadequate information or advice as to how to undertake these, how best to use equipment and what to do if problems arise. Assumptions are made about the knowledge or experience of the carer and information is not actively offered, leaving carers uncertain about what to ask and who to approach for advice. At the same time, many carers who have built up vast experience and expertise over the years find their knowledge and contribution to the care of the person may be ignored, or even dismissed. No paid carer would be expected to carry out their role without adequate training nor would their contribution and role within the team providing care go unrecognised in this way.

The difference between the recognition and protection offered to 'professional' paid carers, as against family and friends who are carers, is illustrated where staff properly cannot undertake lifting without suitable equipment, yet there have been occasions where carers have been left to cope as best they can when the necessary equipment has not been supplied for a range of reasons. Current health and safety legislation does not apply to the unpaid carer. There have also been difficulties reported where insurance cover for staff has restricted the options for carers to an 'all or nothing' scenario.

What are we aiming to achieve?

All practitioners need to work with carers as partners and to be pro-active in ensuring carers have full information and advice needed to care. This advice or training should be kept updated as the needs of the person cared for change and as knowledge increases about conditions, medicines and treatment.

Underlying this should be the key principle of services working to ensure the person cared for is able to live as independent a life as possible and preventative and rehabilitative services are part of the tailored package of support.

EXAMPLES

- A Back Care Advisory Service is provided to people in their own homes by the local carers' organisation and funded by the health authority. An advisor provides training in lifting and handling techniques and liaises with other health professionals to ensure the needs of the user and carer are met. The service is monitored through carers completing a simple evaluation card. (*East Sussex*)

- Discussions and workshops have taken place between managers and practitioners within local mental health services and carers to identify carers' concerns, including their need for more information about mental illness. A video has been produced by the carer organisation, Carers in Hertfordshire, for practitioners to raise awareness of the perspective of carers of people with mental health problems. (*East Hertfordshire*)

- Carers are offered training alongside paid care assistants working with people with dementia. Support is arranged to ensure carers are able to take part in the course. (*Tameside*)

- District nurses have responsibilities to provide advice or training to carers and to ensure they know how to use any equipment delivered. Every nurse receives training to be a trainer. Nursing managers regularly check that their staff have addressed carers' needs by auditing records and visiting a small sample of carers in their own homes on a regular basis. The audit is undertaken every three months and a random sample of five records for each team is selected. (*Bolton Community Healthcare NHS Trust*)

- Manchester University is offering training for carers who can select the modules most appropriate to them, for example, on physical conditions or assertiveness. The scheme is being facilitated in Kirklees by Dewsbury Healthcare Trust. Crossroads, Caring for Carers is also providing this training for their paid care assistants. NVQs are awarded to both unpaid and paid carers. (*Kirklees*)

- A twelve module programme of training for carers is being piloted as part of a jointly financed information and training project set up in response to the local Taking Stock and Taking Action workshop. The training will include input from nurses, therapists and other professionals and cover carer welfare rights, relaxation and stress management, lifting and handling and other topics to assist carers. (*Hammersmith and Fulham*)

Where have we got to?

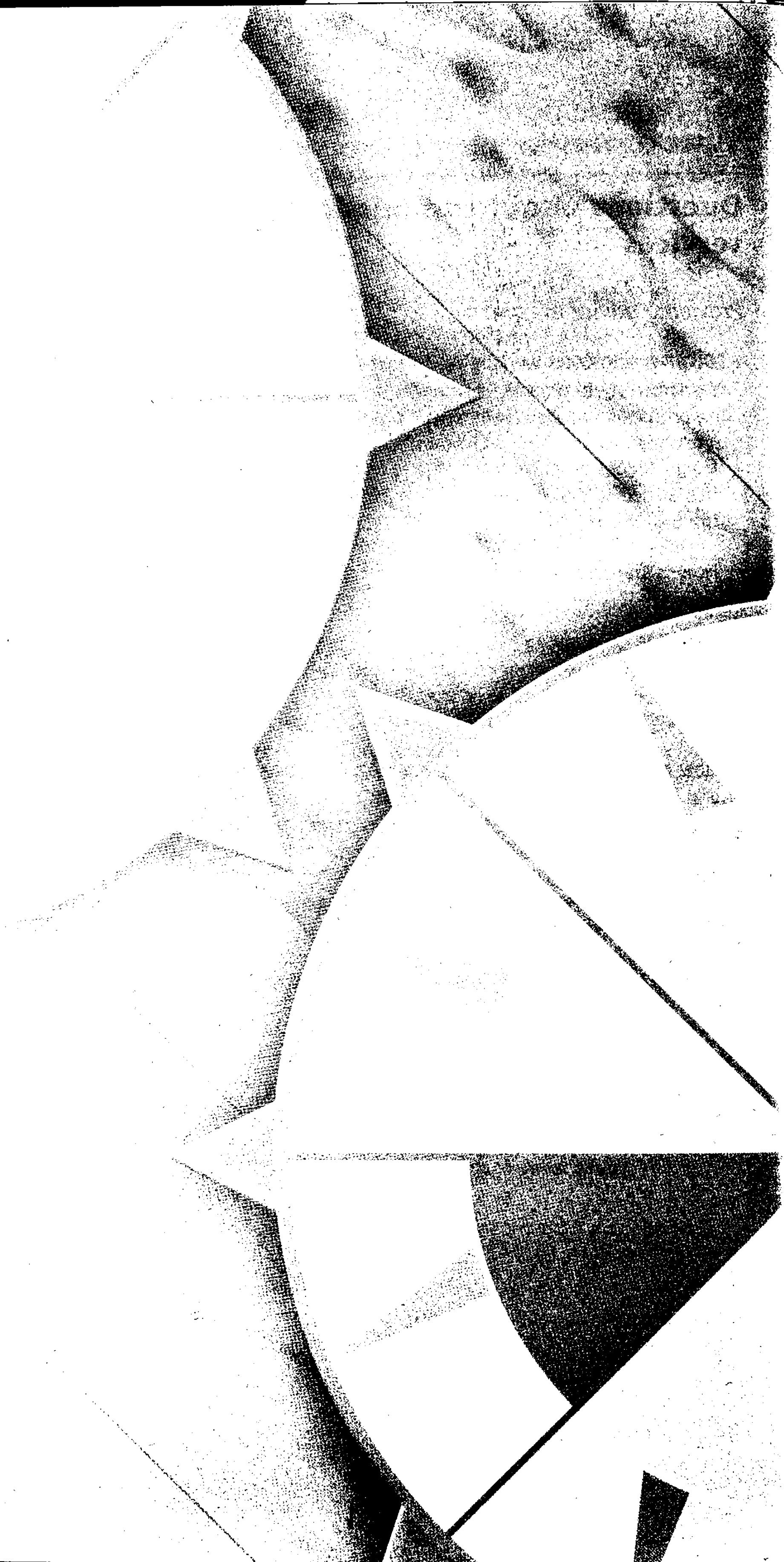
Questions about commissioning and managing services

Providing advice to care

- Do all practitioners working with service users/patients and their carer know of their responsibility to provide, or arrange, the necessary guidance or advice needed by the carer to care, where possible within people's own homes?
- Do guidelines on providing advice to care emphasise the importance of the timing of this advice so that carers are fully equipped to carry out caring responsibilities from the beginning?
- How is staff practice in providing information and advice for carers to care regularly monitored?
- How do you obtain feedback from carers on the effectiveness of this advice?

Arranging courses for carers

- How are you identifying if there is a need for courses for carers, for example, on lifting and handling or on physical and mental health problems? As a start to this, have you mapped out all the current local courses, their accessibility to carers and the actual take-up by carers? Are you consulting carers?
- Have arrangements been made for alternative sitting services and other support so that carers can attend courses?
- How do you evaluate the quality of any courses for carers which you fund?



8 Financial security and carers in employment

> *"Without money there is no choice . . . "*

> *"Carers did emphasise that the costs of caring were considerable and tended to be unrecognised. Extra clothing, heating and laundry costs were frequently mentioned as burdensome, and were difficult to meet within the available allowances. Moreover, a few carers were frustrated at being unable to afford the kind of help which they felt to be appropriate in their own circumstances but which fell outside the parameters of formal support." (Carers Impact report on feedback from carers – Unell and Bagshaw)*

> *"The cost of services was clearly a burden to most carers. Most of them accepted their full entitlement of service at zero or minimal cost but did not take opportunities for extended access because of the extra costs involved . . . The costs of respite care limited the amount that carers could take up, even when encouraged to do so. The worries about cost were exacerbated in some cases by carers who saw the allocation of services as unfair, with some people getting more services free of charge than others." (Carers Impact report on feedback from carers – Unell and Bagshaw)*

The lack of financial security for carers influences every aspect in their lives. Feedback from carers on all the sites emphasised carers' concerns about local charges for services, difficulties in finding and keeping employment and inadequate information about benefits.

What are we aiming to achieve?

Local partnerships can play an important role in improving carers' financial security through:

- carer-friendly employment policies so that carers who wish to can be employed and carry out their caring responsibilities.
- developing training and other opportunities for carers to return to work or to be employed. Employment and training agencies will be important partners to help provide these opportunities.
- providing comprehensive information and good advice about the benefits to which carers are entitled.
- equitable local charging policies about which carers are clearly informed and which are efficiently administered.

EXAMPLES

- An employee census was carried out by the local council and included questions about caring responsibilities to inform future policy development. (*Brighton and Hove*)

- An employment project for carers, funded by the European Social Fund and Surrey County Council Social Services, and run by a carers' organisation, Action for Carers, is working with individual carers and groups to extend employment opportunities for carers. The project is also working with the local business community and employment agencies such as Surrey Training and Enterprise Council to raise carer awareness and promote carer friendly employment policies. (*East Surrey*)

- Following a social services survey with carers and the Carers Impact workshop which highlighted the need for better information and guidance on benefits, a worker has been appointed to provide this advice to carers and to work with benefits advisors to ensure carers are fully informed. (*Kirklees*)

- Work is being undertaken between the Surrey Welfare Rights Union and the local Citizen's Advice Bureau to provide carers with information about welfare benefits and documents and exemptions within the tax system. (*East Surrey*)

Where have we got to ?

Questions about commissioning

Carer-friendly employment policies

- Do all the partner agencies have carer-friendly employment policies and how are these monitored?
- How are carers in the workforce being involved to determine local support?
- Are there a range of support services for staff who are carers? *For example: leaflets about local services, reminders of services in pay slips, telephone helplines, counselling services, informal support groups.*

Helping carers get back into work

- What arrangements are there to help carers locally who may wish to return to employment?
- Are you in touch with local employment agencies, including local TECs, and are these addressing issues within the National Strategy for Carers?

Information about benefits

- How does each partner agency check that carers are receiving, or are directed to, clear information on local charges for services and comprehensive benefits advice?
- Do local assessment procedures make clear the importance of providing carers with information on benefits and charges for services and how is this monitored? (See Appendix 2: Carer Assessments Checklist)

Local charging policy

- What arrangements are in place to ensure:
    - carers receive clear information about local charges
    - administrative arrangements are consistent and prompt?
- What arrangements are there to review the impact of the local charging policy and to check whether the charges:
    - are equitable
    - do not deter carers from receiving or asking for support, including assessments?

EXAMPLES

- Following consultation with managers and staff, the county council carried out a survey of all personnel to raise awareness and to find out more about the caring responsibilities of their employees outside of work and their knowledge of local flexible working practices.

  A leaflet has been produced for all staff *Juggling Working and Caring* to provide information on the advice, support and practical assistance available. It clarifies the issue, defining who is a carer, the effects of caring and the support needed. The leaflet lists the flexible working practices and special leave arrangements available; other services and support which carers can access through social services and carers organisations; and counselling and financial advice offered to employees. (*Hertfordshire*)

Questions about managing services

- What arrangements are in place to ensure all practitioners and staff know about local flexible working practices?
- How is the uptake of these staff benefits monitored?
- What systems are in place to ensure practitioners and staff:
  - provide, or direct carers to, information about any charges for services
  - carry out benefits checks as a routine part of practice when assessing the needs of carers or put carers in touch with specialist benefits advice services?

9 Ensuring carers have a voice

> *"There is now the opportunity to energise partnership working: between organisations, with service users and their carers to reflect better their wishes, with local communities, and with the voluntary sector." (Department of Health 1998 Modernising Health and Social Services: National Priorities Guidance 1999/00-2001/2)*

Carers' uneven experiences of having a say in their individual contact with services is mirrored in their haphazard engagement in the planning, development and monitoring of different services. Whilst some agencies have considerable experience in involving carers and have been developing an ongoing dialogue with a growing network of carers, others are at very early stages in involving either the person cared for or the carer. Even those agencies with a good track record of working with carers say they are concerned about the numbers of carers who are never involved, particularly those from black and minority ethnic communities. Other agencies have not differentiated between users and carers, and carers report very mixed experiences of having their voice heard.

Working with carers on strategic and planning issues was a new experience for some of the managers taking part in the Carers Impact two-day Taking Stock and Taking Action workshops. Real concerns were expressed before the days about 'opening the floodgates' and raising expectations which could not be met by the statutory agencies. However, by the end of these workshops and from feedback from the demonstration sites very clear benefits were identified by all the agencies of involving and working alongside carers. These include:

- better understanding by all the professionals of the real needs of carers, their priorities and what really makes a difference for carers
- a 'freeing-up' of discussions previously dominated by professional and agency boundaries so that a more holistic view of people's needs is taken, encouraging a whole systems approach and assisting in 'cross-cutting planning'
- a sharing of a wide range of expertise, experiences and perspectives which encourages more lateral and imaginative thinking
- immediate feedback from carers' experiences of policies, services and practices to assist in standard setting and monitoring

What are we aiming to achieve?

The experiences of the Carers Impact sites also highlighted some well-rehearsed issues which need to be addressed to ensure an effective engagement with carers. These include:

Clarity and shared expectations between all the partners as to:

- the nature of the engagement
- what it is trying to achieve
- the timescale, ensuring adequate time for all the partners, including carers, to be properly involved
- the roles and responsibilities of all the partners
- who will make decisions and what will be the outcome

Recognition that no one individual can represent all the carers or all the professionals

- two-way communication needs to be developed with wider carer and community networks
- arrangements for informing and engaging with other managers, practitioners and staff need to be in place within all the partner organisations

Sensitive facilitation in the engagement

- so that carers have an equal voice
- everyone is kept fully informed throughout the process

Support to all the partners

- practical support for carers, such as expenses and substitute care
- training or briefings for carers
- training or briefings to all the other partners

Regular reviews of progress to ensure

- the focus has not been taken over by other agendas
- any new members are fully involved

Regular feedback to carers to identify the changes made as a result of their involvement

Checklist for engaging with carers

> *"The aim is to achieve an inclusive process with the accent on the widest possible local involvement from the outset, rather than consultation on a near-final product" (Health Improvement Programmes: Supporting Guidance Department of Health 1998)*

- Has a strategy for involving carers been agreed between all local agencies and carers ?
- Does this strategy clarify:

  The degree of involvement

  - Will carers simply receive information about services and any changes?
  - Will carers be consulted on a given agenda or prepared draft document?
  - Are carers seen as equal partners where the agenda for any work will be agreed from the beginning?
  - Will any carers be delegated control of a service or decision making powers?

  Activities in which carers will be involved. *For example:*

  - Planning and commissioning – including needs assessments, identifying priorities, determining desired outcomes
  - Setting and monitoring standards
  - Evaluating services and their impact
  - Training and raising the awareness of staff

  How carers are supported to take part

  - Are carers who take part on planning and other groups supported by carer organisations, other carers or support workers so that they are not 'lone voices' and have two-way feedback with other carers?
  - Are carers given the necessary practical support to take part ?
  - Are pre-meeting briefings arranged where appropriate ?
  - Are interpreters and other facilitators provided?
  - Are carers with any special needs properly supported to take part?

How carers from all communities and of all interests are included

- Are networks and contacts of all the partner agencies to be shared in order to reach a broad cross section of the local carer population?
- Is outreach work to minority communities to be resourced?
- Are staff who go out to people's homes being briefed as one way of engaging with carers who cannot get out to take part in meetings?
- Is work to raise general awareness of carers being undertaken?

How an ongoing dialogue with carers is to be encouraged

- Is there a variety of approaches; for example: newsletters, phonelines, local radio, newspapers, briefing of community groups?
- Do managers regularly go out to speak to carers individually in their own homes or in carer groups?
- Do carers have direct representation on the local social services committee as a co-opted member?
- Does a member of the health authority or trust board have a designated special interest in carers?

How this involvement will be reviewed and monitored from the carers' viewpoint and from all the other partners' perspectives

- for example, through an annual review with carers and all the agencies participating and an agreed plan of action
- through the evidence of increased numbers and a wider cross section of carers becoming involved

EXAMPLES

- In Greenwich, two forums for carers meet up to four times a year to feed issues into joint commissioning and their Joint Investment Plans. One forum is for black and minority ethnic carers, primarily Asian carers, and the other forum is facilitated through the local carers' centre. Carers unable to attend meetings are able to be involved and have a voice through a questionnaire sent out regularly in the centre's newsletter which provides carers' feedback on services. An invitation has been sent out to all the carers on the centre's local register inviting them to share their expertise by getting involved in monitoring services, assisting health and social services recruit staff and in joint planning. (*Greenwich*)

- In Ealing, the monthly meetings of the Carers Consortium has helped to keep up the momentum of joint work to support carers and bring together carers and the health, social services and voluntary sector to share ideas, avoid duplication, identify funding and work on local priorities. The Consortium has proved to be a valuable focus for carers' issues and has linked with corporate work, for example, on one-stop shops. It is working to achieve wider ownership of the issues. (*Ealing*)

- A group of service users called SUCAT (Service Users and Carers as Trainers) is being funded to be fully accredited as trainers. They will then be commissioned by health and social services to provide training sessions for practitioners and staff. (*Durham*)

- In Kirklees, the Working in Partnership Project is developing its consultation with service users and carers, steered by a joint group representing health, social services and the voluntary sector. A project co-ordinator and development officers facilitate the work. A carers forum meets three times a year and a network of carers is developing. These carers are involved with services in a range of ways, such as focus groups, telephone surveys and consultation with residential homes. (*Kirklees*)

- Southampton City Council policy is to use the Carers Association for consultation on carers' issues. Carers are represented, for example, on a consultation panel for users and carers; a City Council Sub-committee; a planning group for people with learning difficulties; a charging policy task group; Best Value project workshops and Southampton City Council Housing Project for disabled and vulnerable people. (*Southampton*)

- St Helens Social Services Department holds a quarterly carers and workers forum which provides an opportunity for an exchange of information and for carers to have a voice. (*St Helens*)

- The focus groups held for the Carers Impact demonstration projects were one helpful way of obtaining the views of carers on local services and boosted the confidence of some carers to take part in joint work to develop services. The focus groups were run by facilitators independent of local services so that carers were able to comment freely. The groups were structured in a way that encouraged people to think broadly about the issues as well as to give personal feedback.

Lessons from the Taking Stock and Taking Action programme

The core of this programme was a two-day workshop which brought together about 40 people from health, social services, the voluntary sector and carers to produce action plans for improving support to carers. This proved to be a very inclusive and helpful process, providing a kick-start for ongoing partnership working and not dependent on any pre-existing infrastructures. The benefits of this process include:

- **Building local partnerships**, both in bringing together new players as well as developing linkages where previously there may have been competition or rivalry.
  - *stakeholder mapping which identified all the key partners who needed to be involved was an important part of planning the workshops*
- **Developing shared ownership** through understanding the whole picture of needs, local and national priorities, and working together to find creative solutions
  - *everyone took part in creating a 'time line' or map of the work undertaken locally, providing both personal and organisational experiences; sharing their views on what did and did not work; and thinking about trends and changes, such as legislative, demographic and political influences*
- Providing an opportunity to identify and debate the values of the different stakeholders and **forming a common value set** to assist in setting criteria and priorities for services
  - *people discussed underlying principles and drew up a picture of the 'ideal future' before moving on to identify practical steps forward*
- **Encouraging all the participants to take responsibility** for action planning and evaluation beyond the workshop
  - *workshop participants took part in a process to achieve agreement about realistic priorities and then to start action planning, identifying each of the steps needed to reach their goal and how they would know when they had got there; all the participants knew there would be a follow up review*
- **Providing an opportunity to streamline cross-cutting planning** and offering an approach which makes sense to carers who are not caught up in agencies' unreal divisions of responsibilities
  - *carers felt more comfortable in contributing their own experiences where agency boundaries were put aside and where 'joined-up thinking' was encouraged, so that, for example, transport was seen as having links to health issues*

The process offers valuable experience for the partnership working which needs to take place to inform the core content of the Health Improvement Programme and other joint strategies.

10 The Carers Compass for Primary Care

Why should Primary Care address carers' issues?

Carers are an investment Carers – family, partners and friends – provide the majority of community care and the costs of the care they provide, which includes personal and emotional support, treatment and 24-hour supervision, could never be replaced by health and community care services.

There is evidence that it is cost effective to support carers who can prevent patients unnecessarily returning to hospital and who provide long-term care, often without any support from either the NHS, social services, other members of their family or the local community.

Carers are 'patients' too Carers' health may be at risk because of their role and there is evidence that their health problems, including depression, back and upper limb injuries, may be overlooked.

Carers are partners Carers have an important contribution as they have a unique role in the whole system of caring, with experience of using services and with expertise in caring

Central directives The National Strategy for Carers emphasises the importance of providing information to carers, supporting carers to care and caring for carers' health and well being. Members of the primary care team have an important role identifying carers, assessing their health needs and in ensuring carers know of their rights to an assessment under the Carers (Recognition and Services) Act 1995.

The importance of Primary Care to carers

- Primary Care is in a key position to take early action, to recognise carers, to signpost them to services and support, and to identify any health needs of the carer.
- Carers have a high regard for their GP and community nurses and are likely to turn to them as the first port of call. Many carers are very isolated and may have little knowledge of local services and how they work, other than their GP, or other members of the primary care team.
- Experience shows that carers will not make unsustainable demands, but that carers who are well informed and supported gain confidence to contact the most relevant professional or service and are less demanding on their GP and the Primary Care Team.

Primary Care Groups and their responsibilities

- Primary Care Groups will need to clarify their plans to support carers in line with the joint strategy within the Health Improvement Programme.
- Primary Care Groups will also need to agree how they will involve carers in the monitoring and development of their local plans.
- The quality of services and support to carers by practice teams should be picked up as part of clinical governance.

A checklist for Primary Care Teams to meet the eight key needs of carers and to provide a quality service

1 To be fully informed

- What arrangements have been made so that all practitioners and staff know of their responsibility to:
  - identify patients and service users who are or who have carers
  - always explicitly seek the patient's consent for information to be passed to their carer
- What checks are made to ensure all practitioners and staff:

  1: pro-actively offer carers full information about the illness or disability of the person they care for:
    - what they can expect to happen
    - treatment and medication needs, including the side effects of medication
    - how they can best care for the person

  2: signpost carers to local services and support which offer practical help, emotional support, financial advice and opportunities for a break. (This information may be obtained from one central contact).

  3: provide information to carers on:
    - how to obtain a carers' assessment and why it is important
    - what to do in an emergency
- Has one member of the team/practice been given responsibility to update the carer information and ensure this is made available to all practitioners and to carers?

2 To be recognised and have their own needs, including health needs, taken into account

- What arrangements are there to ensure all practitioners and staff, including receptionists:
  - are carer aware
  - know many people do not identify themselves as carers
  - avoid assumptions about caring based on age, gender, relationship or culture?
- Is there visible evidence in the surgery/health centre that the role of carers is recognised?

For example, is there a carer's noticeboard or are carer publications and information for carers available in the reception and waiting areas? Has a member of the team been given responsibility to keep this information updated?

- Is carer awareness training included within induction and other training programmes and are carers involved in delivering this training?
- Has a system been put in place, as required by the National Priorities Guidance for health and social services, to identify carers and to note this on the practice records, whether the carers are patients of the practice or carers of patients? Has responsibility for marking the records been clearly assigned?
- Are there systems agreed to ensure carer's own health needs are recognised and checked out, particularly at critical times in the carer's and patient's lives?
- Is there an agreed protocol for ensuring carers are informed of their rights to an assessment of their needs under the Carers (Recognition and Services) Act 1995 and why assessments may help them? Are carers referred to social services for an assessment or told how they can obtain an assessment and what it entails?
- Are carers able to speak privately to any member of the team if they wish?

3 Quality Services

- What checks are made to ensure carers are listened to and no assumptions made, for example, that they will automatically continue to care regardless of the level of illness or disability of the patient?
- What evidence is there that practitioners sensitively negotiate agreement between the carer and person cared for where there is any conflict ? Do they involve an advocate if it is appropriate?
- Is there a flexible system for appointments which can help the carer who may have difficulties going out to the surgery or health centre or who may find certain times very difficult because of their caring responsibilities?
- What arrangements are there to ensure continuity in service delivery so that wherever possible the carer sees the same person or team of people?
- What systems are in place to ensure carers know how to get help in an emergency and who to contact?
- Is there an alert marker on patient's and carer's notes where there is a potentially violent situation which a carer may not be able to safely mention when contacting their doctor or out-of-hours services?

4 Opportunities for a break

- What checks are made to ensure all practitioners are aware of the importance of a break for the carer and know where to signpost carers to obtain help in finding a solution which suits the needs of both the carer and patient?

5 Emotional support

- What monitoring arrangements are there to ensure practitioners and staff listen carefully to carers and offer advice, or signpost carers to services or carer groups which can provide emotional support?

- Is there a local carers' support group which meets regularly at the surgery/health centre or near by?

6 Training and support to care

- Do all practitioners have clear responsibilities to ensure carers have the appropriate advice and training to care, for example in lifting, medication, changing dressings, giving injections, hygiene, nutrition and emergency first aid?

- Does the practice/health centre provide sessions for groups of carers which give advice on caring as well as individual advice sessions within the carer's home?

- How is one-to-one advice to carers and group sessions monitored?

7 Financial security

- How are carers signposted to information and organisations which offer advice on benefits? Is it clear who has responsibility for this and is this monitored?

- Do local organisations hold regular benefits advice 'surgeries' for carers?

- Do managers follow good practice in providing flexible working conditions for staff who are carers as well as in paid employment?

8 Having a voice

- Do carers have opportunities to tell the Primary Care Team about their experience of services and is this feedback taken into account when shaping and developing local services?

- Are carers' issues being addressed by the Primary Care Groups and how is the Primary Care Team encouraging and facilitating a dialogue between carers and members of the Primary Care Group?

Appendix 1

The Carers Impact Programme 1996–99

Aims of the programme

The Carers Impact programme started in 1996 and aimed to build on the work of the first programme which ran between 1992–95 and to address three key challenges:

- To bring more areas up to a point where they have an agreed plan of action to improve carers' support
- To demonstrate improvements in carers' lives through the implementation of strategies i.e. to ensure strategies are not merely paper exercises
- To increase the profile of service developments taking place in order to inspire and inform a more concerted approach to carers' support throughout the country

The programme was supported by an alliance of statutory, professional and voluntary organisations concerned to see change. The Department of Health and the Gatsby Charitable Foundation funded the three-year programme based at the King's Fund.

How we worked

The programme took two separate developmental approaches designed for areas at different stages in their work to support carers:

- *The Taking Stock and Taking Action* programme was suited to those authorities at early stages in their joint work, particularly the new unitary authorities, and aimed to act as a 'kick-start' to agreeing joint action plans
- *The Demonstration projects* were designed to investigate what makes a difference in the lives of carers in areas who were further on in their joint strategic work and who were ready to test out the impact of their work

Taking Stock and Taking Action

Thirteen sites self-selected to take part in the Taking Stock and Taking Action programme: Brighton and Hove, Ealing, East Surrey, Greenwich, Hackney, Hammersmith and Fulham, Kirklees, Milton Keynes, Shropshire, Southampton, St Helens, Sunderland, and Windsor and Maidenhead.

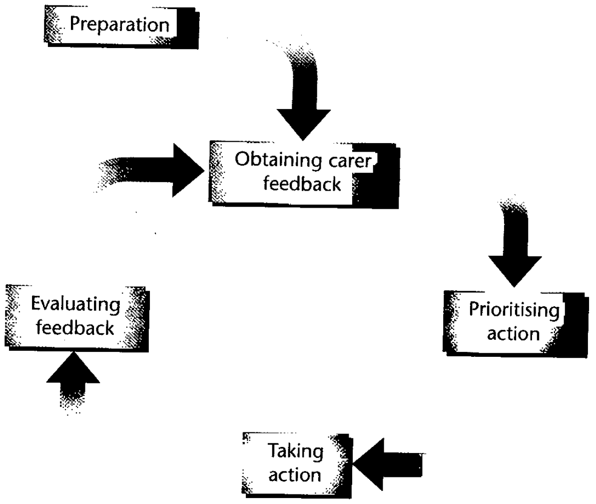
The core of this programme was a two-day workshop engaging all the key partners from health and social services, the voluntary sector and carers. The workshop, facilitated by a member of the Carers Impact team and one outside development consultant, reviewed the action that had been taken locally to support carers, shared views on where the work should be heading, agreed priorities and produced practical action plans to forward the work.

A review of progress in implementing the action plans was initiated by Carers Impact after a year. All the partner agencies were involved, including carers, in assessing the action taken and identifying how the work would continue.

Demonstration projects

Six sites have taken part in longer term projects which have aimed at focusing on the outcomes for carers of health and all local authority services, voluntary organisations and carers working together. Bolton, Durham, East Sussex, Hertfordshire, Southwark and Tameside were selected from joint applications submitted by health and local authorities as offering a geographical mix and different approaches to developing carer support.

These projects started by speaking to carers about the impact of services on their lives and this feedback, obtained through semi-structured interviews and focus groups run by independent researchers for Carers Impact, was used to set the agenda for action on each of the sites. A member of the Carers Impact team worked alongside the multi-agency group set up to lead the work. This group, which included carers, prioritised, co-ordinated and monitored the action taken in response to the issues raised by carers. At the end of 12–16 months Carers Impact spoke to carers again to obtain feedback on the impact of the work and this was used to inform a joint evaluation with the site on the changes achieved.



Appendix 2

Carer assessments checklist

Checklist for frontline and reception staff

- Do you identify the existence of an actual or potential carer in each situation?
- Do you have a positive manner and listen carefully to build up a rapport with carers and to assist people to identify they are carers and convey the impression that it is not wrong to seek help?
- Are there any linguistic, communication, cultural or religious issues with which you may need to obtain assistance in order to help the carer?
- Do you give carers information about their rights to an assessment, how it might help them and how they can obtain one?
- Do you signpost carers to services which offer information and support?

Checklist for practitioners carrying out assessments

Before an assessment

- Have you offered the carer a choice of place and time for the assessment?
- Have you given the carer written information about assessments which explains about the benefits of assessment and what will happen?
- Have you given the carer the name and number of a contact person if problems arise before the assessment meeting?
- Have you involved all the relevant people in preparation for the assessment so carers do not have to repeat information?

At the assessment meeting

- Have you *explained to the carer what an assessment* is and what it is for, how the meeting will be conducted and what will happen next – and checked they have understood?

- Have you *provided the carer with all the information they need,* including:
  - carers' rights under the Carers (Recognition and Services) Act 1995
  - who qualifies for support from social services
  - services which may be available from social services, health and other local agencies
  - any charges for services
  - local carer organisations and groups
  - the condition of the person cared for
  - advice or any special information needed to care
  - what to do in an emergency
  - welfare benefits for the person cared for and for the carer
  - how to make a complaint
- Have you *listened carefully to the issues the carer wants to raise?*
- Have you *looked at all the needs of the carer and understood:*

  What the carer does

  - their responsibilities and the tasks they undertake and any health effects for the carer, including emotional effects
  - what they are not able to do because of their caring responsibility
  - any tips for services from the carer's experience of how best to work with the person cared for

  What practical help is needed

  - whether they need any other practical help, equipment, housing adaptations advice, support

  Whether they can get a break

  - whether they get a break and some time for themselves

  The effect of caring on the carer and family

  - the extent or level of the relationship before caring started and the positive and negative effects of having to care on this relationship
  - the effect of caring on themselves both now and as they see the future, including satisfaction and difficulties
  - the effect of being a carer on the carer and other members of the family

After the assessment

- Have you let the carer know the outcome of the assessment and sent the carer a copy of the care plan?
- Have you kept the carer updated on when the services will be provided and any amendments to the plan?
- Have you agreed a date to carry out a review and does the carer know how to request a review?
- Have you recorded any unmet needs?
- Is it clear to the carer and to all the agencies involved who will be co-ordinating all the different services and how these will link with any other input from informal and other networks?

Appendix 3

Proforma for a joint strategy and Implementation plan

Health Warning: The development of a local joint strategy should be the result of all the partner agencies working together with carers!

Introduction

- Which chief officer groups/committees have commissioned this work?
- Who developed this strategy and action plan, and when?
- What it is about?
    - definition of carer
    - brief local profile – potential numbers/characteristics of carers
- Why it is important to support carers – their role and expertise.
- National Strategy, National Priorities Guidance and legislation (detailed in Appendix to the strategy).

Present position

- Brief description of current local policies and services relating to carers

Context – external and local issues

- Brief summary of key factors which are likely to affect support to carers over the next three to five years – those outside the control of the partner agencies and those which could be changed or reviewed locally.

Underlying principles

- See, for example, the key principles in the introduction to the Carers Compass: Directions for Improving Support to Carers, or the New Carers Code produced by the Carers National Association which sets out ten key principles.

Statement of intent

- What the partner agencies would want services and practice to look like; for example:
  - that *all* services recognise and respond to carers, not just specialist services
  - that all the local agencies work together with carers to improve support to carers
- How this strategy relates to other connected strategies and policies, for example on hospital discharge, continuing care, mental health, rehabilitation.

Key priorities

- The priorities the partner agencies have agreed to work upon, including opportunities for a break.
  - See, for example, the eight outcomes around the Carers Compass which carers have identified as important to them.

Action Plan to implement the strategy

- For each priority specify:
  - objectives
  - tasks
  - timescale
  - action by (key people; named)
  - funding
  - how this will be monitored/performance measures

How this strategy will be monitored and reviewed

- Who will be responsible for co-ordinating the actions and reviewing progress and how this will take place.
- How carers will be kept informed.

Appendix 4

Useful References

Banks P, Cheeseman C, Maggs S *The Carers Compass: Directions for improving support to carers* King's Fund 1998

Baker G, Syverson C *Primary Care Projects Directory* Carers National Association 1998

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Appendix 5

Carers Impact Steering Group

Rosanne Corben: *Chair;* Peter Ackland: *Alzheimer's Disease Society;* Debbie Allen: *Crossroads Caring for Carers;* Jean Bailey: *Royal College of Nursing;* Jill Pitkeathley (until Nov 1998)/Diana Whitworth: *Carers National Association;* Andrew Cozens: *Association of Directors of Social Services;* Amanda Edwards (until Feb 1999)/Claire Gazdar: *Social Services Inspectorate;* Jeff Jerome: *Local Government Association;* Harry Marsh: *Contact-a-Family;* Chris Vellenoweth (until July 1998)/Janice Miles: *The NHS Confederation;* Stella Lowry (until October 1997)/Bill O'Neill: *British Medical Association;* Janice Robinson: *The King's Fund;* Matthew Williams: *Gatsby Charitable Foundation.*

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This practical guide aims to help commissioners and managers from the NHS, local government, voluntary and independent sectors improve local support to carers in line with the National Strategy for Carers.

Using the experience of the Carers Impact programme, questions are posed about commissioning and managing services which are designed to help joint working and individual agencies move from planning to delivering better support to carers. Examples are given from work on 19 Carers Impact sites around the country to illustrate how different areas have moved forward their work in partnership with carers.

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