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Briefing Paper

Access to health care for carers

Almost seven million adults in Britain care for sick, elderly or disabled friends and relatives on an unpaid basis. Caring is physically and mentally demanding, and many carers say it has a negative impact on their own well-being. But despite this, carers' health needs often go unaddressed. Sometimes this is due to professionals not recognising or understanding these needs. Sometimes it is due to difficulties getting an appointment that fits around their caring responsibilities. It may even be because carers prioritise the health of the person they are caring for, at the expense of their own. However, evaluations from a range of projects show that there are positive steps that can be taken to improve carers' access to health care.

This briefing is for practitioners working in primary care teams, primary care trusts, NHS trusts and the voluntary and community sectors, as well as carers themselves. It explores the barriers facing carers, as well as some solutions, and it makes recommendations for primary care trusts and GP practices. It is based on a review of the research evidence and a consultation with key stakeholders on barriers and interventions in relation to health care access for carers (Arksey *et al.*, 2003). The study focused on primary care and respite services, due to the lack of information on carers' access to hospital care, specialist health services, national screening programmes and dental, optical or chiropody services. See *About the study* (page 6) for further details.

About carers and their health

i. One in six adults cares for a sick, disabled or elderly person. A quarter of these provide care for more than 20 hours a week

ii. 40% of carers say caring affects their physical or mental health

iii. Half of those providing care for more than 20 hours a week report a long-standing illness. More than a third say this illness limits their activities

iv. During a typical life span six in ten people are likely to have caring responsibilities which take up more than 20 hours a week.

General Household Survey, 2000 (i – iii); Hirst and Hutton, 2000 (iv)

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NHS Service Delivery and Organisation R&D Programme

The policy *context*

The work of unpaid carers means that more elderly and sick people are able to remain in their homes and local communities. This in turn reduces pressure on hospitals and residential care. In recognition of this contribution, government policy over the last ten years has sought to address the needs of carers and to look at ways of supporting them in their caring role. Some of the key developments are:

- The national strategy for carers (1999) recognised that carers might neglect their own health because of the demands of their caring responsibilities and took steps to address this through the Carers Special Grant
- The Carers and Disabled Children's Act (2000) built on the provisions of the Carers (Recognition and Services) Act 1995 to give carers greater entitlement to an assessment of their ability to provide care
- The *National priorities guidance* (1998) gave a commitment that GP surgeries would routinely identify the people in their practice who are carers. The likely vehicle for taking this forward is the electronic patient record. Practices are now entitled to additional funding if they have procedures in place to identify carers and refer them to social services for an assessment of their needs.

There are also a number of policy initiatives to improve health care access for everyone, which by implication should improve access for carers. These include NHS Direct, walk-in centres, healthy living centres and the Access, Booking and Choice programme.

The barriers to *health care access*

Despite this policy commitment, many carers face obstacles to accessing and using health care services. To find out more about these barriers, the research team carried out a review of all the relevant literature in the field. Using rigorous quality and relevance criteria, they identified 32 studies exploring the barriers facing carers. They also identified 14 evaluations of projects specifically designed to address the needs of carers. The majority of these were delivered in primary care, community or home settings.

Box 1 summarises and categorises the barriers identified in the first set of studies, the solutions identified in the second set of studies, and the research team's recommendations in response to these findings.

The following section provides further detail about the key research findings on the barriers to health care access. The researchers grouped these into five broad areas:

Professional responses: Almost half of the studies in the review identified barriers created by the attitude, values or working practices of professionals such as GPs and nurses. Contributors to the consultation felt that professionals tended to focus on the person being cared for, rather than the carer. They also felt that the focus on responding to immediate health needs and crisis situations made it difficult for health professionals to offer preventive approaches which encouraged carers to take positive and early action to stop problems arising.

Service organisation and delivery: The way that services are structured and operated was frequently cited as a barrier to access. For example, one study found that fewer than 25% of GPs and only a third of nurses routinely recorded whether someone was a carer. In the consultation, the cost of health services was felt to be a deterrent to some carers, as some types of preventive health care (such as flu vaccinations) had to be paid for even though they were offered free to other vulnerable patient groups, staff and paid carers.

Box 1: Barriers, solutions and recommendations

Category	Barriers	Different projects have addressed t barriers by:
Professional responses	• Lack of recognition of carer role • Lack of awareness of carers' needs and the issues involved • Professional uncertainty about the roles of and boundaries between different professional groups • Focused on reacting to problems, rather than promoting good health • Priority given to the care recipient at the expense of the carer • May have stereotypical view of carers that is not conducive to meeting their needs	• Promoting the role and needs of carers among members of the primary care team • Treating carers as partners • Encouraging general practice staff to champio carers and oversee changes in practice
Service organisation and delivery	• GP surgeries not identifying carers or 'tagging' their records • Lack of training for primary care staff on carers' issues • Reception staff can make it difficult for carers to get appointments • Inflexible appointment systems • Long waiting times • Lack of transport and car parking facilities • Cost of certain treatments, such as vaccinations	• Developing systems for identifying carers and ta • Providing special appointments • Providing services more flexibly • Enabling carers to refer themselves to services • Providing health care in the home or other no • Using software packages to help plan service
Language or culturally held beliefs and practices	• Carers not being able to speak English • Inadequacies in translation and interpreting services • Racial prejudice and stereotyping by health professionals • Professionals' lack of knowledge about cultural and religious practices	• Using different community facilities to actively ethnic minority carers • Encouraging the development of more positiv attitudes *Note that neither the literature review nor the contribut identified specific remedies to overcome access barri*
Carer characteristics	• Carer not prioritising their own health • Carer not wishing to seek help • Carer holding certain beliefs or preferences which prevent them seeking help • The person receiving care may act as a barrier, for example by refusing respite care	• Identifying supportive professionals to activel to seek help and advice at an early stage, reinf information • Using telephone and computer technology to • Holding carer support groups
Lack of information and knowledge	• Carer not being given information about available services and how to access them • Concerns over medical confidentiality which prevent health professionals discussing the needs of the care recipient	• Providing accurate, up to date information to carers • Signposting carers to other agencies • Providing carers with the technology (at home settings) and the knowledge to access inform • Providing skills training to carers (for example,

Language or culturally held beliefs and practices: Though the evidence in this area is relatively weak, some studies showed that language and cultural issues could restrict access. For example, carers who did not speak English were unable to talk about their emotional needs to English-speaking staff. This meant that professionals were less able to support them psychologically. In the consultation, contributors pointed out that carers in this position might not attend health appointments with the care recipient and so would remain invisible to health staff.

Characteristics of carers: There was relatively strong evidence that the approach, behaviour and values of carers can have an impact on the way they access health care. One study found a significant association between the level and intensity of caring, and not finding time for doctor appointments or forgetting to take medication. Some carers preferred to obtain help anonymously. This was particularly true of young people, who worried about confidentiality issues. In the case of respite care, several studies noted that carers felt guilty and selfish if they used these services.

Lack of information and knowledge: Half of the studies identified barriers that prevented carers getting hold of knowledge and information that would support them in their caring role. Medical

hese	Recommendations for future practice in primary care trusts and GP practices
g GPs and other on the needs of	• Train all health professionals and front-line staff to identify and accept carers as a discrete group with specific health needs, adopt carer-sensitive practices as part of routine patient care and ensure familiarity with changes in policy, practice and legislation • Initiatives and incentives to ensure professionals focus on carers' health issues
gging carers' records s on-health venues provision	• Provide health care services in settings which are accessible and acceptable to carers • Identify and tag carers' medical records • Identify or employ a highly visible point of contact/carer support worker in each practice or service • Implement a system for identifying and addressing the needs of carers that suits the particular size, staff mix and working culture of individual practices
y reach out to ve professional *ors to the consultation* *ers in this area*	• Expand professional interpreting and translation services as well as assistance with reading, writing and form completion • Use community resources to advertise carer initiatives to reach carers from black and ethnic minority communities • Provide cultural diversity training for health care professionals in cultural and religious issues and appropriate practices
y encourage carers forced by written o provide anonymity	• Educate carers about the benefits of health promotion behaviours and regular screening • Help carers recognise, acknowledge and address their own caring role, through work with voluntary and social services
professionals and or in community ation themselves how to lift correctly)	• Introduce initiatives and procedures to overcome professionals' concerns about medical confidentiality issues • Make medical and service information available in a variety of languages and media • Ensure health care professionals have access to up-to-date information on national and local services for carers in the voluntary and community sectors

confidentiality was a particular issue. Carers often had difficulty finding out important medical information about the people they looked after because health professionals felt they had to respect the confidence of their patients, even if sharing the information would help the carer provide better care.

Overcoming the barriers

Government programmes to improve access to health care for everyone can help overcome some of the obstacles faced by carers, in particular service barriers such as waiting times and the flexibility of appointment times. However the research shows that they face a range of other barriers which are unique to being a carer. Tackling these barriers is likely to require action specifically focused on carers, though there is a policy tension here between the drive to improve the 'absolute' level of access for all and helping those whose needs are greatest.

Box 2 highlights three projects that have overcome some of the barriers facing carers, while **Box 3** includes a selection of guidelines and toolkits that have been produced to help primary care services and carers themselves.

Areas for further research

There are a number of gaps in the existing literature and evidence base. Further research into the following areas is recommended:

- Carers' access to health care in their own right, not in relation to the care recipient
- Carers' access to health care in settings other than primary care, for example hospital, dental and optical care and national screening programmes
- Carers' use of generic NHS services such as NHS Direct, NHS Direct Online and walk-in centres
- The evaluation of local primary care projects, in order to develop transferable and sustainable approaches and to identify the impact on particular carer groups
- Culturally sensitive services, in particular what it means in reality to have 'culturally sensitive' health care services for carers
- Information and communication technology, to inform the development of local, national and international e-health websites for carers
- Specific carer groups, such as young carers, older carers, black and ethnic minority carers, and carers in rural areas
- Outcome measures, with the aim of reaching agreement among different professional groups about appropriate measures to gauge the effectiveness of interventions
- Economic evaluations to highlight the financial implications of different interventions.

Box 2: Supporting carers in practice

These projects, along with 11 others, were discussed in the research study because they had been evaluated in a sufficiently rigorous way to be included in the literature review. They give an indication of different ways of supporting carers.

Brent Primary Care Project

In this example of close working between the voluntary and statutory sectors, two project workers from Brent Carers Centre were based in the offices of the Primary Care Trust and jointly managed by senior workers in the Trust and the chief officer from the Centre. They carried out direct work with carers, as well as development work with primary care services. They helped a majority of GP practices put in place a system for tagging carers' records and display material from Brent Carers Centre. They also developed a well-received information pack, and provided carers with one-to-one advice and support. There were often competing priorities within the GP practices, so not all felt they could implement carer systems. The dual roles of the project workers meant that the needs of carers were on the agenda at both strategic and practice level, though it did create high workloads.

The ACTION telematics project, 1997–2000

This three-year project ran across England, Northern Ireland, Portugal, the Republic of Ireland and Sweden. Carers were provided with video telephones and access to multimedia programmes on topics such as lifting and handling, respite services and coping skills. Some also received internet and email facilities. The project developed carers' knowledge and skills, which in turn increased their competence in their caring role. Although the system caused some anxiety at first, it reduced carers' sense of isolation, provided easier access to care professionals and created effective informal social networks. Care managers felt that the service would probably be too expensive for many people to fund themselves, though a full economic evaluation was not carried out.

Mobile therapy unit, Dementia Care Trust, Bristol 1999–2002

This project aimed to increase feelings of well-being among carers and people with dementia, through the provision of aromatherapy massage, reflexology or reiki in their own home. The client-carer pairs received one treatment a week over a four-week period. In an independent evaluation of the first year of the project, nearly two thirds claimed that positive changes to their health and well-being were still evident three to five weeks after the last session, and over one third of clients said they sustained lasting benefit.

Box 3: Guidelines and toolkits

The research study also identified eight practical resources to address carers' needs. These were not evaluated, though some were grounded in the available evidence on carers. This box gives an overview of four of them.

Guidelines for primary health care teams: South Asian Carers' Project (Nuffield Community Care Studies Unit, University of Leicester, 1998). This guide contains recommendations to help primary health care teams in their work with carers from the South Asian community.

How good is your service to carers? A guide to checking quality standards for local carer support services (Kings Fund, 2002). This guide aims to help services assess how well they are doing against the five quality standards which were developed as part of the national strategy for carers.

Healthcare for carers (Pharmacia, 2002) is a pack aimed at carers of people with Parkinson's disease. It is the result of a collaborative partnership between a pharmaceutical company, the South West London Community NHS Trust and a number of patient groups. It can be downloaded at **www.healthcareforcarers.co.uk**

'Seven and a half minutes is not enough': a good practice guide for carers, support workers and GP practices (Princess Royal Trust for Carers, 1999). This guide contains advice on developing effective support, including how to identify carers. Suggested measures include changes to appointment systems, handling emergency and out-of-hours enquiries and addressing stress, exhaustion, back injuries and other carer-related symptoms.

About the *Study*

The aim of the study was to inform the NHS Service Delivery and Organisation (SDO) Research and Development (R&D) Programme about the theory and evidence on carers' access to health care. Its two key objectives were:

- To examine the evidence from UK and international research (published and unpublished) to identify problems and barriers for carers in accessing health care services and evidence of interventions to improve carers' access to health care services
- To consult with key stakeholders with an interest in carers' access to health care about the findings from the review and recommendations for further research.

The research methods were:

A literature review: Using a range of search strategies and a clear protocol to guide the process, the team initially identified 8775 studies. Of these, 46 were of sufficient relevance and quality to enter the review. The majority (32) discussed barriers to accessing health care or respite services. The remaining 14 were evaluations of interventions designed to improve accessibility for carers. The reports were classified in terms of type of study design and strength of evidence. Some of the studies were stronger and more robust in comparison with others, which had implications for the conclusions that could reasonably be drawn.

A consultation: Policymakers and practitioners with an interest in access issues were consulted as part of the study. These included 12 national statutory and voluntary sector organisations and eight local organisations that had introduced interventions specifically to improve carers' access to health care. The consultation complemented the review findings, and helped to ensure the relevance of the report's recommendations for practitioners and service users.

The study report documents key themes from the literature review and consultation. It categorises the barriers according to five key characteristics (see **Box 1**) and suggests solutions and recommendations. It also outlines a model of access to health care specifically for carers (not discussed in this briefing). A supplementary report provides detailed information about the interventions reviewed.

References and further reading

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1 Social Policy Research Unit, University of York, **2** Department of Social Policy and Social Work, University of York, **3** NHS Centre for Reviews and Dissemination, **4** Acton.Shapiro, **5** The late Sally Baldwin was a professor in the Department of Social Policy and Social Work at the University of York.

Further *Information*

The full reports and this briefing paper can be downloaded at www.sdo.lshtm.ac.uk/access.htm

About the SDO Programme

The SDO R&D Programme is a national research programme managed by the National Co-ordinating Centre for NHS Service Delivery and Organisation Research and Development (NCCSDO) under contract from the Department of Health's R&D Division.

For further information about the NCCSDO or the SDO Programme visit our website at www.sdo.lshtm.ac.uk or contact:

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Box 1: Barriers, solutions and recommendations

Category	Barriers	Different projects have addressed these barriers by:	Recommendations for future practice in primary care trusts and GP practices
Professional responses	• Lack of recognition of carer role • Lack of awareness of carers' needs and the issues involved • Professional uncertainty about the roles of and boundaries between different professional groups • Focused on reacting to problems, rather than promoting good health • Priority given to the care recipient at the expense of the carer • May have stereotypical view of carers that is not conducive to meeting their needs	• Promoting the role and needs of carers among GPs and other members of the primary care team • Treating carers as partners • Encouraging general practice staff to champion the needs of carers and oversee changes in practice	• Train all health professionals and front-line staff to identify and accept carers as a discrete group with specific health needs, adopt carer-sensitive practices as part of routine patient care and ensure familiarity with changes in policy, practice and legislation • Initiatives and incentives to ensure professionals focus on carers' health issues
Service organisation and delivery	• GP surgeries not identifying carers or 'tagging' their records • Lack of training for primary care staff on carers' issues • Reception staff can make it difficult for carers to get appointments • Inflexible appointment systems • Long waiting times • Lack of transport and car parking facilities • Cost of certain treatments, such as vaccinations	• Developing systems for identifying carers and tagging carers' records • Providing special appointments • Providing services more flexibly • Enabling carers to refer themselves to services • Providing health care in the home or other non-health venues • Using software packages to help plan service provision	• Provide health care services in settings which are accessible and acceptable to carers • Identify and tag carers' medical records • Identify or employ a highly visible point of contact/carer support worker in each practice or service • Implement a system for identifying and addressing the needs of carers that suits the particular size, staff mix and working culture of individual practices
Language or culturally held beliefs and practices	• Carers not being able to speak English • Inadequacies in translation and interpreting services • Racial prejudice and stereotyping by health professionals • Professionals' lack of knowledge about cultural and religious practices	• Using different community facilities to actively reach out to ethnic minority carers • Encouraging the development of more positive professional attitudes *Note that neither the literature review nor the contributors to the consultation identified specific remedies to overcome access barriers in this area*	• Expand professional interpreting and translation services as well as assistance with reading, writing and form completion • Use community resources to advertise carer initiatives to reach carers from black and ethnic minority communities • Provide cultural diversity training for health care professionals in cultural and religious issues and appropriate practices
Carer characteristics	• Carer not prioritising their own health • Carer not wishing to seek help • Carer holding certain beliefs or preferences which prevent them seeking help • The person receiving care may act as a barrier, for example by refusing respite care	• Identifying supportive professionals to actively encourage carers to seek help and advice at an early stage, reinforced by written information • Using telephone and computer technology to provide anonymity • Holding carer support groups	• Educate carers about the benefits of health promotion behaviours and regular screening • Help carers recognise, acknowledge and address their own caring role, through work with voluntary and social services
Lack of information and knowledge	• Carer not being given information about available services and how to access them • Concerns over medical confidentiality which prevent health professionals discussing the needs of the care recipient	• Providing accurate, up to date information to professionals and carers • Signposting carers to other agencies • Providing carers with the technology (at home or in community settings) and the knowledge to access information themselves • Providing skills training to carers (for example, how to lift correctly)	• Introduce initiatives and procedures to overcome professionals' concerns about medical confidentiality issues • Make medical and service information available in a variety of languages and media • Ensure health care professionals have access to up-to-date information on national and local services for carers in the voluntary and community sectors

This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene & Tropical Medicine.

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