

Working with carers: guidelines for good practice

Definition

A carer is anyone who, without pay, looks after a relative or a friend who because of their disability, state of health or the effects of old age, cannot manage without that help.

Introduction

There are at least six million unpaid carers in Great Britain and Northern Ireland, and 1.25 million provide at least 50 hours of care a week.¹ One in five households contains a carer.² Sixteen per cent of carers are over 65, and half of those being cared for are 75 or older.³ Many are 'round the clock' carers.

Carers are the bedrock of the care and support system; the vast majority of care needs are provided by unpaid carers at home. The economic value of unpaid support that carers provide to our society has now reached £87 billion a year according to a recent study,³ potentially equivalent to the cost of providing another NHS. This contribution of carers deserves recognition and an understanding by health professionals that they act as partners in care.

Without these carers, many more people would need long-term admission to hospital care, home placements or expensive home support packages.

What legislation and guidance relates to carers?

Where carers live makes a difference

With devolution, each part of the United Kingdom has different provisions for carers. More information on individual rights can be obtained from the relevant office of Carers UK. See below for contact details or visit the website: www.carersuk.org

Carers' basic rights – England, Wales, Scotland and Northern Ireland

Doctors are often the first point of contact for patients and carers and thus are able to be advocates for patients and carers. Therefore, primary and secondary care teams should be fully conversant with assessment and support mechanisms for carers.

Carers' basic rights are enshrined in the Carers (Recognition and Services) Act 1995, as follows:

- to have their needs assessed by the local authority when it carries out an assessment of the person cared for in respect of community care services
- to have their needs re-assessed should the user's circumstances change
- to have the assessment results taken into account when the local authority makes decisions about services to be provided to the user.

For the purposes of the Act, a carer is:

- an adult who provides or intends to provide a substantial amount of care on a regular basis
- a child or young person under 18 who provides or intends to provide a substantial amount of care on a regular basis
- a parent who provides or intends to provide a substantial amount of care on a regular basis for a disabled child.

The Act covers carers who may or may not be a relative and who may or may not be living with the person for whom they are caring. However, the Act is only one aspect of a range of ways in which carers may be helped.

- Local authorities may continue to use their powers under the 1977 NHS Act to provide or support services such as carer support groups and information. Such services should be available to all carers without requiring an assessment.
- The Disabled Persons (Services Consultation and Representation) Act 1986 requires the local authority to take account of the ability of a carer to provide or continue to provide care when deciding what services to provide to the disabled person.

From April 2007 the Work and Families Act 2006 was extended to give most carers in employment the right to request flexible working. Carers can also request the right to private space at work to help cope with their caring role. Higher than average stress levels have been recorded in working carers and it affects their health. Those who have flexible working say that it makes a difference to their health and wellbeing. These new rights also apply to NHS employees who are also carers.

England and Wales – additional rights

- The Carers and Disabled Children’s Act 2000 gives local authorities the power to supply certain services, which help the carer and the person being cared for, direct to the carer. The Act provides a new right for a carer to be assessed even if the cared-for person has not been assessed. The carer assessment must be reviewed on an annual basis by law.
- The Health and Social Care Act 2001 allows carers to receive direct payments, ie the cash, instead of the care provided by social services though in practice this rarely happens.

The Community Care (Delayed Discharges) Act 2003 placed a duty on social services to assess the carer, if they have not been assessed in the last 12 months, before the patient is discharged. Carers providing regular and substantial care would have the right to request an assessment of their needs. The local authority, after responding, would have to ascertain that the right support was in place for carers to ensure that the patient was safe to discharge.

- The Carers (Equal Opportunities) Act 2004 places a duty on social services to look at whether the carer wishes to work, learn or have leisure activities in their assessment. It gives local authorities the power to request the help of health services to deliver the outcome that is needed. The health service has a duty to consider the request.

Scotland

Carers in Scotland do not have a right to receive their own services unless they are considered disabled or frail and would receive services under other legislation.

Northern Ireland

Carers in Northern Ireland have similar rights to those in England and Wales under the Carers and Disabled Children Act.

Scotland and Northern Ireland

There are additional duties under the Community Care and Health (Scotland) Act 2002 and the Carers and Direct Payments (Northern Ireland) Act 2002 for local authorities to inform carers of their right to an assessment.

Many carers with substantial caring responsibilities may not know about their rights under these Acts therefore health professionals should be able to signpost new and established carers to the relevant carers organisations.

Where the carer is under 18 or the parent of a disabled child, local authorities should also consider whether the Children Act 1989 (or the Children (Scotland) Act 1995 or the Children (Northern Ireland) Order 1995) applies. The Children Act provides a framework for all services for children in need including young carers. It emphasises the need to ascertain and give due weight to the wishes and feelings of children and to promote the upbringing of children by their families. Where the carer is a child the impact of caring may affect his or her health and development and this should be carefully

considered as part of the assessment. It is equally important that the assessment focuses on how best to enable an ill or disabled parent to live independently so that his or her ability to parent is supported rather than undermined.

Identifying carers

One of the priority objectives laid down in the Government's national priorities guidance for England⁴ requires primary healthcare teams and social services staff to identify carers by April 2002. The guidance states that statutory agencies should:

'provide carers with the support and services to maintain their health, and with the information they need on the health status and medication of the person they are caring for (subject to that person's consent). As a first step ensure that systems are in place in primary care and in social services authorities to identify patients and service users who are or who have carers.'

The importance of the role of general practice in recognising carers has resulted in the inclusion of three voluntary quality indicator points in the 2002 GP General Medical Services Contract Quality and Outcomes Framework (QOF). This provides an incentive for practices to have a protocol for the identification of carers and to develop mechanisms for the referral of carers for social services assessment. Primary Care IT systems have dedicated Read Codes for recording carer status, which can be used for this purpose.

The Government's first national strategy for carers⁵ was published in 1999. This set out proposals for development and has three strategic elements:

- information for carers, 'so they become real partners in the provision of the care to the person they are looking after, with the means to provide that care as well as they wish to, and with wider and better sources of information about the help and services available to them'
- support for carers, 'from the communities in which they live, in the planning and provision of the services that they and the person they are caring for use, and in the development of policies in the workplace which will help them to combine employment with caring'
- care for carers, 'so that they can make real choices about the way they run their lives, so they can maintain their health, exercise independence, and so that their role can be recognised by policy makers and the statutory services'.

The new National Strategy for Carers was published in June 2008. It contains a bold vision described as a shared vision and responsibility between central and local government, the NHS, third sector, families and communities. The strategy says that by 2018:

- carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role
- carers will be able to have a life of their own alongside their caring role
- carers will be supported so that they are not forced into financial hardship by their caring role
- carers will be supported to stay mentally and physically well and treated with dignity; and
- children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against all the Every Child Matters outcomes.

In the area of health (and health-related) provision the strategy specifically provides for:

- an increase of £150 million in the amount of money available for breaks. Probably as a consequence of the economic value to the health service of carers the money is to be allocated to Primary Care Trusts (PCTs) who will be required to work with local authorities to publish joint plans for the provision of breaks. Under the Freedom of Information Act, GPs can contact their PCT to ask how the allocation of money for carer's breaks is being spent. The BMA has produced a draft template letter. A copy is attached in Appendix 1.
- pilots looking at existing provision of breaks and encouraging innovative approaches to provision and how personal budgets can be used to provide breaks
- pilots of annual health checks for carers in a number of PCTs
- pilots to provide a training programme for GPs to help them better understand carers' needs which, if successful, may be rolled out nationally

- pilots to look at how the NHS can better support carers. These will include involving carers in diagnosis, care and discharge planning as well as greater support for carers in GP practices and hospitals
- Caring with Confidence, a training programme for carers (formerly known as the Expert Carers Programme) aimed at supporting carers in their caring role and helping them to access their entitlements
- funding over the next two years to give carers comprehensive and up-to-date information about services in their local area. This will complement the national website and information helpline for carers for which funding has already been committed.

What do carers need?

There have been many surveys and investigations of carers' needs.^{6,7} A growing body of research evidence suggests that there are broadly six categories of help, which enable carers to cope and to continue to care. These are:

- **Recognition of their role and contribution**

It is essential that carers are involved in plans for care. A survey by Carers UK found that half of carers felt their comments and concerns were not taken into account.⁸

Carers want to be seen, not just in terms of the services they provide to the person being cared for, but as a person in their own right with their own physical, social and emotional needs. Carers UK has found that carers expressed a great deal of satisfaction with doctors who treated carer and patient together, and showed concern for the carer's physical and mental health.¹⁰

- **Opportunities for a break from caring**

Time off from caring gives carers a chance to recharge their batteries or attend to self care. This can be achieved through respite offered by care attendant services, sitting services provided by volunteers or paid carers, day care, volunteer befriending schemes, family placement and other schemes. There is funding from Government for this provision although this can be difficult to access.

- **Receipt of reliable and satisfactory services**

In particular, carers have highlighted the following as important to them: help with bathing, toileting and lifting, house cleaning, and maintenance and gardening. It is not always possible for carers and those they are caring for to make use of services that necessitate travel. Healthcare support in the home (chiropractic, physiotherapy, and bathing) is therefore important, and the BMA's Committee on Community Care welcome the opportunity to support doctors who are concerned if these services are withdrawn, rationed or unavailable to their patients and their carers.⁸

- **Information**

The range of information required by carers is wide and should be tailored to each individual need. For instance, carers often need comprehensive information on the health needs and treatment of the person they are caring for. This is not only following diagnosis and at the commencement of care but also for established carers. When a carer is involved in helping a person with their medication he or she needs to know how and when it should be taken and be able to recognise any side effects from it. Many carers have this role – a survey of 1,300 carers found that 94 per cent helped to ensure the person took their medication, 23 per cent changed dressings and 13 per cent gave injections.⁹ Carers also need information to allow them to deal with the symptoms of some illnesses and recognise when they should ask for urgent professional help and where to get such help, especially when they are caring for someone with a mental health problem. However, conflicts can arise if a patient is unprepared to consent to information being shared in this way – this is dealt with later in this guidance.

- Patients and carers expect GPs and primary care team members to be well informed on local health and social care provisions and benefits. While it is beyond the role of a GP to have a comprehensive knowledge it is helpful to be able to act as a signpost to direct carers to the appropriate person or place.¹⁰ Carers have said that they value this role particularly as financial worries can be an added source of stress particularly if the carer has had to reduce working hours, or (as happens in one out of five cases) give up work to care.

- **Care for their own health**

Representative surveys have confirmed that carers' own health suffers as a result of caring. This includes not only physical health (primarily musculoskeletal problems) but also mental health, particularly in cases where carers have not been able to take a break from caring. Doctors and primary healthcare staff have a key role in helping to signpost carers so as to ensure that they get the physical and psychological support they need. A survey carried out by *Carers Week* has found that carers valued health checks.

- **Emotional support**

Having someone to talk to is greatly valued by carers, whether this person is a professional, a fellow carer or a friend. Not all carers will want to join a support group or will find it helpful, but research suggests that carers who have links with a support group are better able to continue to provide care.⁵

How doctors can help and support carers

Identifying carers

Ten per cent of a GP's patients are carers but many unpaid carers are unaware of their carer status. If doctors are to help carers they must first discover who they are. This is not a straightforward task but it is worthwhile. It is vital that GPs and other professionals are aware and sensitively address the barriers to the identification of carers, for example cultural expectations that exist within some ethnic groups. Where carers have been identified they feel valued and this both reflects well on the doctor and boosts carer self-esteem. Carers who feel part of the team are more likely to use services efficiently and this brings benefit to doctors.¹¹

In a report on carers, the House of Commons Social Services Committee wrote:¹²

'A major difficulty in identifying carers is that many are reluctant to acknowledge their role. Many carers may be identified through crisis intervention but, for the most part, caring is part of a continuing relationship which may finally result in dependency. In such a relationship a need for outside assistance can be seen as a measure of failure. The first step to encourage carers to identify themselves and to assist future planning is to acknowledge them as individuals and their right to services.'

Self-identification of carers can be encouraged through the use of carer notice boards asking 'Do you help look after someone?' and through leaflets available in surgeries, wards and clinics inviting contact with carers' centres. This is an ideal opportunity for liaison between primary and secondary care particularly after unforeseen medical events such as strokes.

In primary care opportunistic identification during consultations, new patient registration, flu jab sessions and notification of hospital discharge can be effective ways of identifying carers.

Many GPs have a computer template to identify carers for the purposes of the GP contract.

A properly resourced system has the potential to be used to target carers, to provide them with information on relevant services and to keep them apprised of services in the practice, such as training sessions, health checks or carers support group meetings. Effective use of a carers' register is an appropriate use of NHS monies.¹⁰

Practices choosing to identify carers may do so by an initial audit followed by tagging of patient notes with whether the patient is a carer or has a carer – there are specific Read Codes for this. Practices can go some way towards keeping these up to date by regular questions at patient interviews and during health checks.

It is important for GP practices and secondary care to develop a range of supportive services for those that they have identified as carers, eg carer health checks, flexible appointment times and confidentiality protocols. On-site accommodation for carer support workers is a valuable asset.

The *Good practice guide to highlight the needs of carers and carers' health*, was launched at the 'Recognising carers: partners in primary care' conference on 29 October 2007. Jointly developed by the RCGP and the Princess Royal Trust for Carers, this self-assessment toolkit is designed so that primary care teams can measure themselves against agreed criteria for the services they provide for patients and their carers, particularly focusing on teamwork and practice organisation.

Be aware you are part of the network

Carers' issues are often regarded as the province of social services, but often patients and their carers are reluctant to approach social services, as this still seems to carry some stigma, and prefer to contact their GP.¹⁰ It is also possible that carers may not need social services support and the assistance they require can already be found in the community.

There is a network of different professionals and organisations providing a wide variety of services and support, which can help carers. These include:

- local carers' groups, which range from small self-help groups to larger local organisations. These offer a range of support such as information, advice, training for carers including stress management, practical support, advocacy and social activities
- carers' centres, such as those run by Princess Royal Trust for Carers, provide a range of services and often provide carer support workers to perform carer assessments
- Carers UK can put individuals in touch with their local support groups including Carers UK branches by visiting the website: www.carersuk.org or by calling: 0808 808 7777 or 020 7490 8818
- community nursing services
- home care services provided by the Red Cross, Crossroads, the Women's Royal Volunteer Service and other voluntary organisations
- advocacy and counselling services including the Citizens Advice Bureau.

Other services are available from adult services and children's services.

Carers are more likely to use carer support services if they have been recommended by people they know and respect – perhaps a friend, or a professional such as a GP or practice nurse support.¹¹ Doctors and nurses in primary and secondary care should be particularly well-placed to act as a signpost for carers to learn about the network of support available and what it has to offer, as for many carers the initial point of contact is with the NHS.⁵ Carers' groups should be encouraged to pass information about their activities directly to local GPs, primary care trusts and local health groups so that this can be readily accessed and relayed to those who need it.

Carers UK have reported high levels of carer satisfaction with doctors who are aware of the network of support available. For instance, some GP practices, hospitals and social services have issued contact cards, which list telephone numbers for the area of the main services, which support carers. These cards could be augmented by the inclusion of an emergency number for carers' use in the event of a crisis. Ready contact between primary care and hospital consultants (especially geriatricians and psycho-geriatricians), social workers, community psychiatric nurses and other specialist services can all assist in smoothing the way for patients and their carers to find help.¹² Among the initiatives that have been shown to help carers is the attachment of named social workers to general practice and integration with the primary care team.¹⁰

Seeing patients in their home environment means that carers and their needs are much more visible to district nurse and health visitors than practice-based staff.¹² The BMA's Committee on Community Care would welcome the opportunity to defend existing services. With the development of primary care groups and primary care trusts in England, and similar organisations elsewhere in the UK, a dedicated cross-practice person could be assigned to promote services for carers – a 'health visitor for carers'.

Occasionally it can be difficult to persuade carers to take up services, perhaps because of previous poor experiences because the service did not match the need or a desire to be seen as coping. Carers themselves say that it is often difficult to admit they need help particularly when they are so busy dealing with immediate priorities that it can be hard to take a step back and articulate what support is required. In contrast, others feel that help comes too late, and that they have had to wait until a crisis before help is arranged.¹ Having information 'at the ready' is doubly valuable in these instances.

Carers' own healthcare needs

Studies show that caring has a physical and emotional impact on carers' health. A longitudinal study of the British Household Panel Survey found that the health of carers is more likely to deteriorate than improve over time compared with health in non-carers. Carers' physical health was more likely to deteriorate beyond the first year of caring and they were more likely to make additional contact with the GP or practice services during and after caring. The study found that the greatest impact was on carers' emotional health, particularly those providing over 20 hours of care per week.¹³

In terms of emotional impact, further analysis of the General Household Survey found that carers who did not have a break were twice as likely to display signs of mental disorders such as anxiety, depression, phobias etc compared to those who had a break. Carers who provided higher levels of care, lived with the person they cared for and cared for a disabled spouse or child were significantly more likely to have mental disorders.¹⁴

Information and training

This guidance has already described the value to carers of background information about the health needs and treatment of the person a carer is looking after. Not only does this help carers to carry out their role more effectively; it also helps them to plan for the future. Carers also need to be able to access and receive information and training to help them maintain their own health. According to the 2001 Census, carers providing over 50 hours of care per week have two times the prevalence levels of ill-health compared with non-carers. The differences are most stark for those younger carers, ie 20-25 year olds, and decreases with age.

Many carers suffer from physical injury and/or stress as a direct result of their caring duties. A survey by Carers UK found that of those surveyed, over half had experienced physical injury through caring, and a similar number were treated for stress-related illness since becoming carers.⁸ Many of the physical injuries could be prevented if carers received some training in how to move the person they are caring for in a safe and effective way. This can be particularly important at the start of caring.⁵ Services and organisations in the local network of support may already be providing training in the area – this is worth investigating. If not there should be collaboration with other parts of the network to set up some standard programmes.

These might usefully include:

- lifting and handling
- Relevant nursing skills
- use of equipment
- continence care
- stress management¹⁰
- helping carers look after themselves: 'fit enough to care', emphasising healthy lifestyles, relaxation, physical and mental support¹

Professionals have a crucial role in educating carers and giving them permission to think about their own needs at a much earlier stage – before they reach a crisis.¹² Importantly, caring for a relative or friend can sometimes lead to frustration or depersonalisation, but pre-emptive action can avert the possibility of physical or emotional abuse.

A significant number of carers have expressed concern about the lack of recognition of their role by professionals.⁸ At the time of hospital discharge, it is important that carers are involved in the planning of future care of the patient, so that assumptions are not made about their ability and willingness to care.

Studies of carers' views of hospital discharge have highlighted the particular difficulties of failure to involve them in the timing of discharge and of providing little or no information about the future care of the patient.⁵ Before someone is discharged from hospital an assessment of their needs should be carried out; carers can also ask for (and have a legal right to) a carer's assessment to look at the help that they may need as a carer. The carer needs to ask for this assessment from the local adult or children's services department (or social work department in Scotland) of the person they are caring for. If a care plan, and services outlined in it, are not agreed or ready before someone is discharged from hospital, they may be entitled to free intermediate care for up to six weeks while more permanent services are put in place (in England, Wales and Northern Ireland). For further information contact www.carersuk.org/Information/Helpwithcaring/Comingoutofhospital or www.carerscotland.org/Information/Helpwithcaring/Comingoutofhospital

Caring with confidence is part of the Government's New Deal for Carers. The programme, which sits alongside the Expert Patients' Programme, will offer a range of opportunities for carers to develop their own knowledge and skills. The programme will include local group sessions, online and distance learning resources and specific practical training to meet carers' concerns. Carers will be able to mix and match how they further develop their knowledge and skills.

Developing a carer strategy

To coordinate these and other various strands of help and support for carers, it is crucial that all professionals have knowledge of both the national and local Carers strategies. Planning practice-based commissioning should take into account carers need. Supporting carers can save both money and time with shorter appointment times, a reduced number of inappropriate queries, and potential reductions in GP prescription costs (eg antidepressants).¹¹

The following have all been suggested by carer organisations as positive contributions.

- Contact other services to see what has worked elsewhere.
- Provide a carers' literature rack in surgeries or clinics, and make posters for the walls giving information that helps carers or service users identify their carer or cared for status and brief details of services and benefits. Leaflets and carer notice boards will help attract those who have not previously identified themselves as carers.
- Have a specific named contact for carers – a member of staff or a visiting carers' support worker. This person should operate as part of the team with status. He or she will also benefit from support from a specialist carers worker (perhaps from elsewhere in the network) who can help with complex problems and debriefing.
- Provide a quick and easy referral system enabling carers to contact the carers' support worker or project directly.

GP practices could be the location for a 'carer surgery' at a regular time each month – with a support worker or other carers or former carers to pass on information and be a 'listening ear' for new carers. These can be good for solving specific problems and providing in-depth support to individuals. Carers can be referred to the carers support worker or self-refer. Unfortunately in recent years the traditional primary health care team has been disappearing across the UK and any previous potential to provide 'clinics' for carers comparable to baby clinics run weekly, fortnightly or monthly with a doctor, district nurse, health visitor, social worker, and from time to time a representative from social security or the Inland Revenue, has become far more difficult to achieve. Financial imperatives have meant that primary care organisations and local authorities have cut costs and such clinics will require additional investment from these statutory bodies.

Furthermore new access targets have made the opportunity to have special 'carer appointments' to avoid long waits a more difficult aspiration to achieve. Many carers neglect their own health as they cannot leave the person being cared for. However, some GPs are now offering booked appointments outside traditional opening times with appointments of 15 minutes, which could be valuable to carers.

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Professionals need to be aware that each carer's situation is individual and this needs to be reflected when considering a carer's needs because the needs of carers are so variable.

Professionals both commissioning and providing healthcare should **not**:

- wait for carers to identify themselves
- believe that supporting carers will cost too much in terms of time and money
- assume they have to do it all themselves without any specialist support.¹¹

The special needs of young carers

The 2001 Census estimated that there are over 170,000 carers under the age of 18 across the UK.⁵ Many receive no support from statutory or voluntary services. The lives of these young carers are commonly restricted because of the need to take on inappropriate or excessive caring responsibilities. This situation often arises because of a lack of good quality services that are appropriate for their family and a lack of information about how to get support.

Importantly having a parent or sibling with an illness or disability does not mean that a young person is necessarily a young carer.

Research has shown that young carers suffer from specific problems, which are different from those experienced by adults involved in caring. These include:

- problems with education – a lack of time for homework/exams
- isolation from other children and from family
- lack of time for recreation
- guilt and resentment from reconciling conflicting needs of themselves and their parent
- feelings of no one to turn to – professionals working only with the adult patient
- lack of recognition for role
- feelings of difference
- problems in the transition to adulthood (finding work, accommodation, relationships).

Under the Children Act 1989 and the Children (Scotland) Act 1995, young carers can receive support from health and local authorities.

Young carers are difficult to identify because of their silence. This silence is often the result of fear; fear of coming to the attention of professionals and fear of separation from their families either by the institutionalisation of the care recipient or by the instigation of care proceedings.¹⁵

Professional groups need to acknowledge these fears and work with rather than against young carers in order to identify and help them. Parents often share the same fears as their children. Professional intervention often occurs only at times of crisis or when the law is broken. Such intervention is likely to heighten fear and further distance young carers from professionals who may be able to help.¹⁵

Many young carers feel stigmatised because they are different – they do not experience the same type of childhood as other children, and their parents are in some way perceived as being different. Some young carers are likely to be doubly stigmatised – especially those caring for parents with mental health problems or problems of addiction. Many feel they have no one to turn to or that they are letting people down if they talk to someone.¹⁵

Dealing with issues of confidentiality

When asked, many carers say that they would like to have as much information as possible about the condition of the person they are caring for. Possible concerns about confidentiality issues can be overcome if individuals give properly informed consent to their information being disclosed to a third party like this, and that this consent is regularly reviewed. A useful document is the 'Carers in practice' document available via www.rcgp.org.uk and www.carers.org This is accompanied by two documents 'Carers in practice' and 'Carers as partners' which contain a form of consent that is signed by patient and carer in the presence of a health professional. With the permission of a competent patient, it is helpful for both the patient and carer to be involved in discussions about the patient's current and future treatment.

It is important to make the distinction between giving personal information about a patient and giving information about a condition or type of treatment. A carer, hearing about a diagnosis, often wants to know what it means, what will happen etc. If GPs do not have the time to give carers this information, then it is important to signpost them on to disease specific organisations and self-help groups.

The situation becomes more complicated in circumstances where patients do not have the capacity to consent to the release of information about them, choose not to give consent or lack insight into how their wishes significantly infringe the rights of other people to have information that would help them protect their own health.

The General Medical Council's (GMC) guidance *Confidentiality: protecting and providing information*¹⁶ describes the standards of conduct expected of doctors in their professional work. The BMA's guidance *Confidentiality and disclosure of health information*¹⁷ sets out the Association's views and policy, draws together guidance from professional and regulatory bodies and provides advice to doctors on their obligations and responsibilities in relation to the disclosure and use of personal health information. In complicated circumstances like those described above, the GMC and BMA guidance should be consulted in the first instance.

The BMA gives individual advice to BMA members. Please visit the BMA website, www.bma.org.uk or contact askBMA (tel: 0300 123 123 3).

Other support available to carers

People who need help looking after themselves may be able to claim Attendance Allowance, Disability Living Allowance, a War Pensions Constant Attendance Allowance or an Industrial Injuries Disablement Benefit Constant Attendance Allowance.

Carer's Allowance is a benefit specifically for carers. It is available to people who care for someone else for at least 35 hours per week and who are not in full-time employment, if the person they are caring for receives the right level of the above benefits. Carers on a low income may also be able to receive a top up to Income Support, called Carer Premium, if they satisfy many of the conditions for Carer's Allowance.

There are also many new initiatives where carers have been included:

- National Service Frameworks for Mental Health, Older People etc
- The Single Assessment Process – carers are supposed to be part of this
- Patient Advice and Liaison Services (PALS) – an information source for carers

Other sources of information on caring issues for doctors and carers

***Supporting carers: an action guide for general practitioners and their teams* available for downloading as a pdf:** <http://static.carers.org/files/prtc-final-3640.pdf>

Understanding caring – Carers National Association in association with the BMA

This book (£2.50) contains advice on the practical day-to-day business of looking after someone, as well as the support available to carers.

Age Concern – Carers Handbook series

This series of books provides practical guidance and sensitive advice on care, support and advice to help carers. The series includes *Caring for someone who has had a stroke*, *Caring for someone who has dementia*, and *Choices for the carer of an elderly relative*.

Those interested in carers and their needs should contact a national body such as Carers UK or the Princess Royal Trust for Carers for the most up-to-date information.

The Princess Royal Trust for Carers and Young Carers

This provides over 140 carers services around the UK, offering outreach work based in primary and secondary care locations, information, advice and emotional support.

London Office, The Princess Royal Trust for Carers, Unit 14, Bourne Court, Southend Road, Woodford Green, Essex, IG8 8HD

Tel: 0844 800 4361; Fax: 0844 800 4362; Email: info@carers.org; Web: www.carers.org.uk and www.youngcarers.net

Carers UK

20 Great Dover Street, London, SE1 4LX

Tel: 020 7378 4999; Fax: 020 7378 9781

Membership Hotline: 020 7566 7602; Email: info@carersuk.org

Or visit the Carers UK Website www.carersuk.org.uk and CarersLine

These offer benefits and rights information to carers. CarersLine is open on Wednesdays and Thursdays 10am-12pm and 2pm-4pm (0808 808 7777). Both the website and the CarersLine can put professionals in touch with local carers' support groups – a network of around 800 groups.

Contact A Family

This provides specialist advice for families caring for disabled children and children with specific health conditions and helps to put parents in touch with support networks across the UK.

Contact A Family

209-211 City Road, London, EC1V 1JN

Tel: 020 7608 8700; Fax: 020 7608 8701; Minicom: 020 7608 8702; Helpline: 0808 808 3555; Web:

<http://www.cafamily.org.uk/>

Crossroads Caring for Carers

10 Regent Place, Rugby, Warwickshire, CV21 2PN

Tel: 0845 450 0350; Web: www.crossroads.org.uk

Help the Hospices'

Hospice House, 34-44 Britannia Street, London, WC1X 9JG

Tel: 020 7520 8200; Fax: 020 7278 1021; Email: info@helpthehospices.org.uk; Web:

www.helpthehospices.org.uk

Macmillan Cancer Support

Macmillan Cancer Support, 89 Albert Embankment, London, SE17UQ

Tel: 08000 898 500; Fax: 020 7840 7841; Web: www.macmillan.org.uk

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APPENDIX 1

British Medical Association's draft template letter to PCTs requesting information on their allocation of money to fund breaks for carers and spending plans, as referred to on p.3 of the BMA's 'Working with carers: guidelines for good practice'.

Name
Address Line 1
Address Line 2
Address Line 3
Postcode

DATE

Dear Sir / Madam

INFORMATION REQUEST: PCTs spending plans on breaks for carers

As you will be aware in recognition of the valuable contribution carers make to health care, currently estimated at £67bn pa (Institute of Public Policy Research), the Government has committed £150 million over the next two years to fund more planned respite breaks for carers, offering them a break from their caring role and supporting their physical, social and emotional wellbeing. We understand that from April 2009 PCTs have been allocated £50 million of new money to spend on breaks for carers in 2009/10 and £100 million will be allocated in 2010/11. The NHS Operating Framework 2009/10 states in paragraph 37 that "PCTs should work with their local authority partners and publish joint plans on how their combined funding will support breaks for carers, including short breaks, in a personalised way."

We are very interested to learn how individual PCTs plan to spend their allocation of money. Accordingly, we would welcome any information you are able to provide on your allocation and spending plans.

The warmly welcomes the Government's commitment to support respite breaks for carers and the sentiment of the National Carers Strategy which sets out the short-term agenda and long-term vision for the future of care and support for carers, including that carers should routinely be regarded as expert care partners by professionals.

Yours faithfully