



Supporting Carers:

An action guide for general practitioners and their teams



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This resource is a collaboration between the Royal College of General Practitioners (RCGP) and The Princess Royal Trust for Carers. It has been developed with the help of Sheffield University and over twenty GP practices who have piloted and evaluated some of the resources.

The number of carers in the UK is increasing as the population ages and people with disabilities and serious illnesses live longer and are more likely to live at home. This means that home-based and community-based care will rely increasingly on the participation of family and community members as carers. Both health and social care budgets are under growing pressure and the availability of the paid care workforce is declining.

GPs and their teams are usually the first place that carers have contact with the NHS. They are uniquely placed to recognise that someone is, or is about to become, a carer. In some areas, GPs are already the gateway to the huge range of support available to carers. This resource is intended to demonstrate how GPs are already providing support and suggests practical help with action planning to build on your existing good practice.

By using this resource your practice will be able to ensure that:

- The carers who use your practice are recognised and acknowledged.
- Carers, and those they care for, are in better health.
- Your resources are deployed more effectively.
- Sustainable caring is supported, thus reducing the need for secondary and residential care.
- You gain the maximum possible benefit from other services in your area.

This resource helps you to do this by:

- Raising awareness within your team and developing an action plan.
- Pooling your team's knowledge and skills to build on your existing good practice.
- Putting in place systems for identifying carers at the earliest possible stage.
- Identifying and linking to agencies that can help you support carers.
- Supporting employees who are carers.
- Evidencing and sharing your good practice with colleagues nationally.

How to use this resource

We hope that practices at any stage of their carers support services development will find this resource useful.

What this resource includes

- Suggested action and discussion points.
- PowerPoint resources for chapters 1 to 5 to be used to raise awareness and encourage discussion within your team.
- The Self Assessment Checklist.
- An invitation to provide feedback online from your own learning and good practice so that this resource continues to develop and grow.



Foreword from The President of The Princess Royal Trust for Carers

The partnership between The Princess Royal Trust for Carers and the Royal College of General Practitioners has been an extremely informative and productive relationship for both organisations.

It is estimated that 6,000 people take on caring responsibilities every day. Caring can take its toll both physically and emotionally, with the carer's own health and well-being suffering as a consequence of their caring responsibilities. It is vital that carers are identified and supported at the earliest stage possible so that they have access to the support needed. GPs are often the first point of contact which is why they and their practice teams play an invaluable role in the daily lives of carers.

This text clearly illustrates some of the excellent work carried out by GPs, their practice teams and local carers' centres. Since launching the guide in October 2007, I have been impressed with the dedication and the enthusiasm demonstrated in order to deliver a product of the highest standard. The end result, *Supporting Carers: An action guide for general practitioners and their teams*, is a first class piece of work which I hope that you will find extremely useful.

I am confident that this guide will help develop a greater understanding of the issues and support needs surrounding carers. This will not only raise awareness of carers, but it will also encourage knowledge-sharing and learning, all of which will help to improve further support and understanding that carers so desperately need.

A handwritten signature in black ink that reads "Anne". The signature is written in a cursive style with a long, sweeping underline.

HRH The Princess Royal



Introduction from **Professor Nigel Sparrow** **Royal College of General Practitioners**

The relationship between carer and GP practice is a special one and should be recognised as a partnership in care.

GPs and our colleagues in the primary healthcare team can support carers by making them aware of their own health needs, supporting them emotionally and practically and providing useful information.

GPs require accurate information if they are to make efficient diagnoses and carers provide that vital link between patient and doctor. Through their day-to-day relationship with the person they are caring for, the carer is likely to know more about the patient's symptoms than any other professional and is well placed to advise of any changes in the person's condition. This enables the GP to tailor their advice and support.

An estimated 10% of a practice population are carers and there are many more "hidden" carers who for one reason or another are not getting the services and support they need.

The action guide will help GPs and primary care team reflect on the services and care they offer to carers and encourage practical improvements, as well as helping the carer feel supported and valued. It has been designed so as not to create extra work or bureaucracy and we hope it will have a marked impact on the levels of support and services healthcare professionals can provide for carers.

The guide also supports the continuing education of GPs so that doctors can more easily identify patient carers and be aware of their needs.

We hope it will lead to tangible results and new ways of working within the primary healthcare team but perhaps most importantly, it will put carers at the top of the health agenda - where they rightfully belong.

Professor Nigel Sparrow



Introduction from **Sandy Gower FRCGP (Hon)** **Member of the Steering Group**

This guide is arguably our biggest step forward to date in improving healthcare and services for carers.

It will enable the practice to monitor the individual carer's situation and identify problems or issues at an early stage, ensuring that appropriate healthcare, support and information is provided for the carer, as well as the person they are caring for.

It will also enable the practice to share, with consent, information with other agencies, professionals and support networks so that they can prioritise and integrate their services for the benefit of carers. Crucially, the carer may be registered with a different practice from the patient they are looking after and this will mean that, with the carer's permission, the practices can communicate and co-ordinate information more effectively.

The guide has been designed so that it can be used by all members of the practice team, allowing different viewpoints and ideas to be taken into account. It focuses on teamwork – with carers as a vital part of that team – and this can only lead to positive results for carers, the patients they are caring for and the practice team.

A handwritten signature in black ink that reads "Sandra EA Gower". The signature is written in a cursive, flowing style.

Sandy Gower

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“ Every day 6,000 people take on new caring responsibilities ”



Who are carers?

“I don't think of myself as a carer. I just help my Mum.”

Using this chapter will help you to:

Be able to identify a carer and advise your team how to identify a carer.

Calculate how many carers are within your practice.

Defining a carer

A carer is someone who, without payment, provides support to a partner, child, relative, friend or neighbour who could not manage without their help. This could be due to age, physical or mental illness, addiction or disability.

Carers can be described as:

- Family carers.
- Informal carers.
- Parent carers.

A young carer is under the age of eighteen and carries out significant caring tasks and assumes a level of responsibility for another person which is inappropriate to their age. Many disabled parents are wary of the term “young carers” and it should be noted that most children of disabled or sick parents do not have to take on caring roles inappropriate to their age. This situation often arises when parents who have long term conditions are not offered appropriate help and support.

Carers should not be confused with paid care workers, care assistants or with volunteer care workers. We use the term “carer” for clarity and UK legislation. Many people who care dislike the label “carer” altogether, believing it can detract from their identity as parent, child, partner or sibling to the person they care for.

Key statistics about carers in the UK

- One in ten people in the UK is a carer. This equates to six million carers.
- 42% of carers are men and 58% women.
- 175,000 are children.
- 1.2 million carers care for over 50 hours a weekⁱⁱ. This equates to a full time workforce greater than the NHS.
- Around two million people move in and out of caring every year.
- Thirteen million people can expect to become carers in the next decade.ⁱⁱⁱ
- It is estimated that carers save the government up to £87 billion a year.

What do carers do?

Anyone can become a carer and many of us will move in and out of caring roles during our lifetimes. Sometimes a caring role can be taken on unexpectedly following the sudden illness or accident of a relative. There are carers in every community and many juggle their caring role with paid employment. Some care for more than one person and some are themselves disabled, elderly or are young children.

Caring tasks can include providing intimate physical care such as helping someone get up, washed and dressed. They may involve helping to change soiled clothes many



times throughout the day and night. Often carers can carry out a great deal of lifting or assist with mobility. Many manage and administer medication, feeding tubes, colostomy bags or other medical equipment. Carers of people with mental health or substance misuse problems may perform few physical tasks, but provide a great deal of emotional support, including helping to ensure that someone stays safe and responding to incidents of self harm or overdose. The health impacts of this constant responsibility can be just as great as the impact of heavy physical caring. For some, caring can be an all consuming job leaving the carer physically and emotionally drained.

The health and well-being of carers – the facts

Evidence shows that carers suffer poor health and well-being through caring. Carers are at risk from health problems varying from stress-related conditions to injury caused by lifting. The Princess Royal Trust for Carers' confidential online support service for young carers, www.youngcarers.net, has found unexpectedly high levels of self harm amongst the young carers it supports.

- More than 80% of carers say that caring has damaged their health.^{iv}
- Three out of four carers are worse off as a result of caring.^v
- Three percent of carers in Leicestershire reported that they had lost their homes as a direct result of caring. If reflected nationally, this would equate to 177,000 carers.^{vi}
- Half of carers subsidise the disability costs of the cared for person due to inadequate disability benefits.^{vii}
- 14% of carers have had an assessment which has led to a change in support or services.^{viii}

- 28% of young carers have serious problems in secondary school.^x
- Out of all carers caring for more than 50 hours a week, one third report depression, half report disturbed sleep and 25% report back and other strains.^x
- The prevalence of psychiatric morbidity is significantly higher in those who care for others in their own homes.^{xi}

Carers' own access to primary care

Some studies report very low levels of carers accessing GP services when they have health problems. A The Princess Royal Trust for Carers pilot project, aimed at increasing GP and practice awareness of carers, found that its work raised the proportion of carers who felt that their situation as a carer was taken into account upon visiting their GP or nurse about their own health, rose from 33% to 44%.^{xii}

When a carer's health deteriorates to crisis point, the unplanned hospital admission of the carer can sometimes mean that a hospital bed is needed for the person they care for too.

Carers may not visit their GP because:

- Many carers have to obtain respite care before visiting their surgery.^{xiii}
- Carers can only leave the house at particular times of the day.
- Carers services find that carers as a group tend to focus on the health and well-being of the person they are caring for at the expense of considering their own needs.

Calculating the number of carers in your practice population

You and your practice team are already likely to know people who are carers, including those in your practice population and those who are family members or friends. You or someone in your practice team may be a carer or former carer. Caring is a hidden problem however and carers may be unaware that they are carers or that help is available. Out of those new to caring, 42% say that the person for whom they care is reluctant to use care services, thus leaving the carers unable to access any support for themselves.^{xiv}

One in ten people is a carer and so in a practice population of 2,000 patients, around 200 are likely to be carers. Of those about 67 are likely to be caring for more than 20 hours per week, including about 44 caring for more than 50 hours per week.^{xv}

The following table will help you to estimate the number of carers within your practice.

PRACTICE POPULATION	LIKELY NUMBER OF CARERS	NUMBER CARING FOR 20 + HPW	NUMBER CARING FOR 50 + HPW
500	50	17	11
1,000	100	34	22
1,500	150	51	33
2,000	200	68	44
2,500	250	85	55
3,000	300	102	66
3,500	350	119	77
4,000	400	136	88
4,500	450	153	99
5,000	500	170	110

Young Carers

There are 175,000 known young carers in the UK, with 13,000 caring for over 50 hours per week.^{xvi} However, 1.3 million children live with parents who are alcoholics,^{xvii} 2.5 million children live with a parent with a mental health problem^{xviii} and 25,000 with illegal drug misuse.^{xx} Thousands of disabled and ill adults are forced to rely on their children for their survival and well-being. As a result, their children become young carers.

Stress, tiredness and mental ill-health are common for young carers and many experience traumatic life changes such as bereavement, family break-up, loss of income and housing or seeing the effects of an illness or addiction on their relative. There are strong links between being a young carer and underachieving at school.

Most young carers receive no help during their childhoods. Some fear they will be bullied if other young people find out. Families are often wary of services and conceal mental illness and substance misuse, while some parents don't recognise their child's caring role.

The new ten-year National Carers Strategy vision states that those professionals most regularly in contact with





young carers and their families should have the knowledge required to identify problems early on and thus encourage young carers to come forward for the help needed. GPs and hospitals have a vital role to play.

The Princess Royal Trust for Carers, together with The Children's Society, has been funded by the Department for Children, Schools and Families to deliver training, information and best practice examples to local authorities and health agencies in England. Using new Key Principles of Practice and a Whole Family Pathway online resource, the training and support packages will

assist all agencies to deliver the outcomes of the new National Carers Strategy and Every Child Matters to this vulnerable group using a Whole Family Approach. Information packs are also available for GPs as well as a notice board poster and short information leaflet. More information about training and publications is available from www.youngcarer.com.

Action and discussion points

ACTION

Estimate the number of carers in your practice.

Raise awareness of carers' issues within your practice team.

Use this background information to inform action planning.

RESOURCE

Refer to table on previous page.

Discussion points in this chapter and corresponding PowerPoint slide.

See Chapter 4.

DISCUSSION POINTS FOR YOU AND YOUR TEAM

- Which groups of carers is this practice already in touch with?
- Which groups are most likely to be hidden or hard to engage?
- What do we do to identify carers?
- At what points could we do more to identify carers?
- Respecting confidentiality, is the team able to share caring situations and the challenges and/or the opportunities they represent?
- How do our confidentiality practices impact upon carers?



2

What are the benefits to your patients and practice in developing your work with carers?



Using this chapter will help you to:

Understand the benefits to patients, and ultimately your practice, of allocating resources.

Identify possible carers in your own workforce and provide them with support.

Why put resources into supporting carers?

Chapter 1 outlined the health and support needs of carers themselves and demonstrated the clear evidence that, without support, carers are particularly likely to experience poor health and well-being. This chapter will show the benefits to patients and ultimately your practice, of allocating resources in order to identify and work with carers. The underpinning belief here is that patients benefit when carers are treated as partners in care.

Partners in care

With 1.2 million carers caring full time, some around the clock, and 80% reporting ill-health due to lack of support in their caring role, it is not hard to see the positive impact that supporting the unpaid caring workforce can have on the local health economy. The 2007 national consultation for the Prime Minister's new ten-year National Carers Strategy found that carers placed recognition and the provision of information as some of their highest priorities for change.

GPs also require accurate information in order to make effective diagnoses. Carers and family members are likely to know more about the patient's symptoms than any professional. Carers often report that they feel diagnoses have been made on misleading impressions gleaned from short visits or appointments.

Carers' information needs include:

- Carers support services, benefits and entitlements.
- Health conditions and disabilities.
- How to help care for a patient when attending appointments with the person they care for.
- Support to patients attending on their own to consider what impact their condition may have on others around them, who might support them and what information they might need.
- How the carer can maintain their own health.

Key points at which carers need information in order to make informed decisions regarding taking on a caring role:

- ✓ At the point of diagnosis or first concern for the patient.
- ✓ In the lead up to hospital discharge.
- ✓ When the patient's health or circumstances change.
- ✓ When the carer's health or circumstances change.

The Princess Royal Trust for Carers and The Royal College of Psychiatrists produced a series of leaflets for mental health professionals to promote information sharing under the banner Partners in Care. These contain useful information about mental health conditions for carers as well as useful suggestions for all health professionals. The leaflets can be found at www.partnersincare.co.uk.

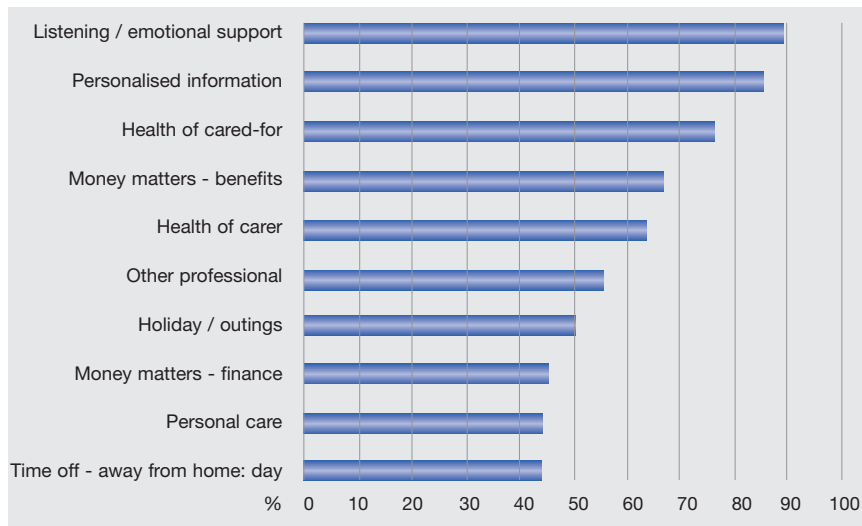


Chart 1

Supporting carers who work for your practice

There are four million carers of a working age.^{xx} Most practices will already employ a carer or someone who will become a carer during their career. That person may even be you.

Carers find it difficult to balance work and caring:

- More than half have given up work to care.^{xxi}
- On average carers retire eight years early and thus miss out on years of income and pensions contributions.^{xxii}

Carers who are supported by their employers to stay in employment can be that organisation's most loyal and dedicated staff. However many simply leave work when a caring role becomes substantial, believing that they have no alternative or because they are unwilling to discuss the situation they are in with their line manager. Your employees who are carers will benefit from:

- A written policy on supporting carers.
- HR policies that encourage positive responses to requests for flexible working, unpaid leave, compassionate leave or even career breaks.
- Reduced workload at times when caring responsibilities increase alongside flexible hours.
- A carer friendly culture so that they know they will be able to broach a caring situation with their line manager in confidence.
- Supportive colleagues and managers with meetings arranged around caring responsibilities.
- Recognition that they may need to stay in touch with home during work hours.
- Carer support services and effective care provision for the person they care for.

Larger companies have developed annual questionnaires for all staff to ascertain how many are carers and how supported they feel.

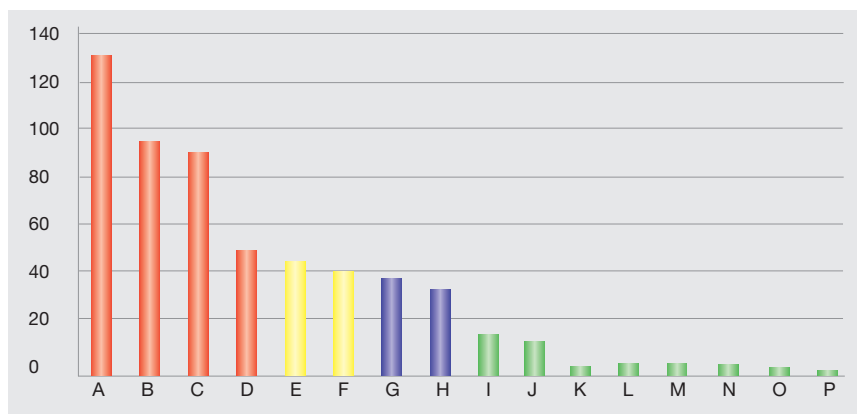
A Carers in Employment Charter has been developed which you and your team may wish to adopt. This can be found at the end of this resource or you can download it from www.carers.org/professionals.

The evidence base for supporting carers through primary care

EVIDENCE A

The Carers Resource in Harrogate, Craven and Airedale, a member of The Princess Royal Trust for Carers network, has produced some compelling evidence showing how treating carers as partners in care uncovers and meets unmet need. Chart 1, above, shows that emotional support, listening and information are the top priorities for many carers. Chart 2 demonstrates the huge difference in numbers of carers accessing specialist support, between carers registered at GP practices working with the Carers Resource and those registered at practices who are not.

For more information, please contact Anne Smyth at director@carersresource.org.



- Practices which have hosted linked Carers Support Office throughout project
- Practices which have had linked Carers Support Officer in later stages of project
- Practices undertaking joint carer initiatives with The Carers Resource
- Practices with no formal contact with The Carers Resource

Chart 2

The Carers Resource carers registered at Airedale practices

EVIDENCE B

Torbay Council commissioned Manchester PSSRU to evaluate the use of Carers Support Workers in GP surgeries in 2002. General Health Questionnaires (GHQ) were used with 68 randomly selected carers. There was a highly significant reduction in distress amongst the carers during the time they received the service from the Carers Support Workers. Despite over half of carers saying that they were in good health, overall GHQ scores at referral/commencement were high, indicating the presence of a variety of psychiatric symptoms. In fact, in terms of a traditionally used cut off score on the GHQ-12 (1/2) to identify cases of psychiatric disorder in primary care, 94% of the carers could be identified as having psychiatric disorders at Time 1. After receipt of the Carers Support Workers, the proportion of carers who could be identified as symptomatic cases reduced by 21%. In particular, the proportion of carers experiencing problems with concentration and sleeplessness reduced substantially. The majority (70%) found the Carers Support worker to be ‘very helpful’. In addition, the majority of carers perceived the service as making a difference to their situation. Whilst 56% were of the opinion that the Carers Support Workers ‘very much’ made a difference and 31% felt that they made ‘a little difference’.

For more information, please contact James Drummond, Torbay Care Trust at jamesdrummond@nhs.net.

EVIDENCE C

Carers in Hertfordshire undertook some in depth research with carers in one GP practice in their area. They compared outcomes for a sample of carers who had been referred to the carers’ centre for information

and support with those who had not. Carers who were referred were:

- Twice as likely to feel well informed about rights and services.
- Twice as likely to know what to do in a crisis.
- Five times as likely to have had a benefits check.
- More likely to have had a break in the last year.
- More likely to use alternative care services.
- More confident about accessing leisure, education or work.

For a full copy of the Hertfordshire report, please see:

www.carersinherts.org.uk/pdf files/Publications /GPCarers_Sep05.pdf

Alternatively, please contact Sue Reeve, Carers in Hertfordshire on 01992 586969.



Employment charter

“Carers are an integral part of the patient's support system. They are the ones with the day-to-day experience of the patient's condition, and they carry the most intimate responsibility for the patient's welfare. The carer's voice in decision making about admission and discharge is ignored at everyone's peril – and yet so often is.”

Dr. Mike Shooter, psychiatrist and former president of The Royal College of Psychiatrists

Action and discussion points

ACTION	RESOURCE
Develop a carers policy in conjunction with your staff team.	See sample Carers in Employment Charter.
Incorporate positive policies on flexible working requests within HR procedures.	See Action for Carers in Employment resources at: www.carersuk.org/Employersforcarers/ACENational .
Request carer training for your staff and managers from your local carers support services.	Find your nearest service at: www.carers.org .
Monitor the prevalence of carers within your team.	Use annual staff appraisals/reviews or an annual questionnaire.

DISCUSSION POINTS FOR YOU AND YOUR TEAM

- How do we currently meet carers' information needs?
- Where could we make improvements?
- What are the staff team's training needs in relation to supporting carers?
- Do our HR procedures help carers balance working for us with caring?
- Does this practice need to develop a charter for carers employed by the practice?

3

What's the policy context?



Using this chapter will help you to:

Have a greater understanding of the policy surrounding carers.

The recent gains for carers

National government has demonstrated strong support for the carers' agenda. The first ever National Carers Strategy in 1999 did much to raise the profile of carers. There is now a New Deal for Carers which includes a new ten-year Carers Strategy, and has much more ambitious aspirations to ensure that the carer of 2012 is supported, healthy, listened to as a partner in care, free from poverty and able to enjoy a life outside of caring. The government has promised to create a national help and advice line, funding for emergency planning and support and an expert carers' programme entitled Caring with Confidence. Information on the New Deal for Carers is at:

<http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Carers/NewDealforCarers/index.htm>

Three Carers Acts enshrine the right of carers to an assessment of their needs, although many carers are still not offered an assessment as they should be and take up is low.

The Work and Families Act 2006 extends the right to request flexible working to carers of adult partners or relatives, or an adult living at the same address. There is provision for a new national insurance credit for carers.

The Carers Grant has established widespread local carer support through third sector carers' centres. There is an indicator within the new National Indicator Set from which every local authority must choose its improvement targets, relating specifically to carers: "NI135 Carers

receiving needs assessment or review and a specific carers service, or advice and information."

NI135 is also a Tier 3 optional local indicator for health trusts within Vital Signs, as are carer-related indicators such as:

- The proportion of all deaths that occur at home.
- The number of delayed transfers of care.
- The proportion of people with long term conditions supported to be independent and in control of their condition.
- Parents' experience of services for disabled children.

In Scotland, the Community Care and Health (Scotland) Act 2002 introduced new carers' rights, and the Care 21 report *The Future of Unpaid Care in Scotland* sets an ambitious ten-year agenda. In Wales, there is now a Carers Champion at government level.

Vital Signs and the new National Stroke Strategy

Vital Signs^{xxiii} (guidance on implementing the 2008/09 NHS Operating Framework) begins with delivery of the National Stroke Strategy^{xxiv} as a compulsory Tier One indicator for all services. The Stroke Strategy includes a range of Quality Markers for NHS bodies to work towards. These markers are very relevant to carers:

- QM1** Members of the public and health and social care staff to be able to recognise the main symptoms of a stroke and know that it needs to be treated as a medical emergency.
- QM3** People who have had a stroke, and their relatives and carers, have access to practical advice, emotional support, advocacy and information throughout the care pathway and lifelong.
- QM4** Involving individuals and their carers in developing and monitoring services.
- QM10** Stroke-specialised rehabilitation within hospital, immediately after transfer to home or care home and for as long as it continues to be of benefit.
- QM11** Active end of life care.
- QM12** Transfer of care from hospital to community needs to be improved, working closely with the voluntary sector.
- QM13** A range of services needs to be locally available to support the individual long term needs of people who have had a stroke and their carers.
- QM14** Assessment and review of the needs of people affected by stroke (including their carers).
- (QM15 and QM16)** Opportunities to participate in and community life and to return to work (for both patients and carers).

Hospital discharge and other health and social care interfaces

Local authorities and health trusts have a duty to cooperate, according to hospital discharge legislation,^{xxv} local government^{xxvi} and health reforms. This means that carers should benefit from the attention focussed on interfaces between health and social care.



New legislation and guidance advises that carers must be involved in discharge planning.^{xxvii} This is backed up by Single Assessment Process guidelines the hospital discharge of older people. Even where patients say they do not want an assessment, the hospital must notify social services of their wish for an assessment to be offered if they cannot establish “whether a patient who says they can manage alone will be safe to discharge without social services’ support or whether the patient’s carer(s) are genuinely able and willing to provide all the support required”.^{xxviii} “Where the carer will be undertaking lifting, or other tasks that need training to ensure that the carer or patient is not put at risk, staff should ensure that appropriate training is provided.”^{xxix}



End of Life Care

Carers often play a vital role in supporting patients through a terminal illness and this has been recognised in the End of Life Care Strategy.

The End of Life Care Strategy sets out three key principles about how carers should be involved and supported in end of life care:

- Carers should be treated as 'co-workers' with the health and social care team.
- Carers have their own needs which should be addressed.
- The condition of the person who is cared for should not affect how the carer is treated, or the services the carer may be able to access.

The End of Life Care Strategy and leaflet for patients and carers can be downloaded from www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277

Personalised support

Putting People First is the concordat between national government, local government and the NHS. It will introduce personalised approaches to adult social care such as greater choice and control of Direct Payments and Individual Budgets. It places carers at the heart of personalisation and recognises the context of changing family structures, such as:

- An eighty year old woman having to cope with her husband's dementia.
- A young mum pursuing a career and bringing up a family while looking after her elderly parent.
- A business executive working overseas whose widowed mother is hospitalised overnight following a stroke.

- Older parents seeking the right support to ensure that their adult son with a learning disability can live independently.

The concordat acknowledges that caring responsibilities will impact on an increasing number of citizens. System-wide transformation of social care will include:

Family members and carers to be treated as experts and care partners other than in circumstances where their views and aspirations are at odds with the person using the service or they are seeking to deny a family member the chance to experience maximum choice and control over their own life. Programmes to be supported which enable carers to develop their skills and confidence.

Policy challenges

Despite the progress on carers policy at a national level, in some areas between national aspirations and local experiences of carer support, there remains a considerable gulf.

Carers Grant rose from £185 million (2007-08) to £221 million (2008-09), but it is not ring-fenced and there is evidence that some councils may not be spending their total allocation on carer support. Every carer should be offered a needs assessment taking into account work, education and leisure. However, actual rates of assessment remain low and carers are not guaranteed to receive the support they are assessed as needing.

Whilst many areas have commissioned third sector carers information and/or breaks and respite services which usually offer a range of support services for free, many of those services have precarious funding and statutory carers support services may be charged for by councils. Council eligibility criteria for adult services in most areas are rising, and the Commission for Social Care Inspection (CSCI) has noted in its State of Social Care reports that this increases the burdens placed

upon carers. Legislation on supporting carers largely enables, rather than creates, duties on councils to support carers, whilst NHS Trusts have no legal duty towards carers. This can lead to confusion amongst statutory services when services for cared-for people are transferred between adult services provided by the local council and NHS Continuing Care.

The new National Carers Strategy 2008

The National Carers Strategy, Carers at the heart of 21st century families and communities, announced £255 million of new funding commitments. Primary Care Trusts receive £150 million over two years for breaks and respite. The new commitments include:

- Providing every carer with comprehensive information through support to local services.
- £150 million to PCTs for flexible breaks which meet the needs of both carers and the people they support.
- Pilots for more joined up service provision between the NHS, local authorities and the third sector.
- Pilots to improve the support offered by GPs for carers and pilot annual health checks for carers.
- Training to strengthen and empower carers in their caring role.
- Training professionals across the board, from health to housing, to provide better services and support.
- Six million pounds to ensure young carers are protected from inappropriate caring and receive support.
- Considering replacement care for carers to attend hospital appointments and screenings.
- Review legislation around information sharing, especially where mental capacity is an issue.

The government acknowledges that the success of the strategy will depend on the extent to which councils, health trusts and individual professionals are inspired by its vision. By 2018, carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, whilst enabling the person they support to be a full and equal citizen.

High Quality Care For All. NHS Next Stage Review Final Report and Draft NHS Constitution

The final report of Lord Darzi's NHS Next Stage Review sets out a ten-year vision for the NHS, alongside a draft NHS Constitution. The ten-year plan includes some commitments on carers, cross-referenced to the detailed commitments in the National Carers Strategy:

- "The NHS locally is seeking to forge a new partnership between professionals, patients and their carers." (p20)
- "Personal care also considers the needs of the patient within the context of their support network, including carers, family and employers." (p21)
- "Increased control will not be limited to those being cared for, but will also extend to carers. A new strategy has been published, setting out the government's plans for supporting carers." (p41)

The Draft NHS Constitution begins with seven key principles to "guide the NHS in all it does". Principle Four is: "NHS services must reflect the needs and preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment."

The Constitution sets out existing legal rights and responsibilities and makes some new pledges above

and beyond those legal rights, including: “The NHS will strive to work in partnership with you, your family and carers.”

The Constitution sets out six underpinning NHS values, including: “Working together for patients. We put patients first in everything we do, by reaching out to staff, patients, carers, families, communities, and professionals outside the NHS. We put the needs of patients and communities before organisational boundaries.”

Chapter 5, section D sets out, one of the challenges of delivering a carer-friendly health service, is reconciling these two responsibilities given to all NHS staff by the draft constitution:

- You have a duty to protect the confidentiality of personal information that you hold.
- You should strive to involve patients, their families and carers in the services you provide.

A full copy of the report can be found at:
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825.

Young carers

Around three million children in the UK have a family member with a disability.^{xxx} Most are not young carers, but whilst no family should have to rely on the inappropriate caring role of a child, thousands find themselves in this situation. Few parents want their children to be carers, but it can happen because there is inadequate support available for the disabled person or because the family is too afraid of outside interference to ask for help.

- The 2001 census estimates that there are 175,000 young carers in the UK (2% of children) and 13,000 care for more than 50 hours per week.
- Latest NSPCC research suggests that 4% of children will be young carers at some point during their childhoods.^{xxxi}
- Government estimates that 250,000 young people are living with parental substance misuse.^{xxxi}
- 1.3 million children live in homes where one or both parents have an alcohol problem.^{xxxi}
- 57% of known young carers are girls, 43% are boys.^{xxxi}
- We support carers as young as five years old.

Most areas have young carers services, but few councils and health trusts have joint working protocols between their new childrens and adults services departments. It is this joint working between childrens and adults services which is required to reduce the number of children in inappropriate or harmful caring roles. The Children Commissioner for England, in his report on Children and Young People’s Plans (CYPPs), states that young carers are a “much neglected group”. Few schools have a lead staff member for young carers, as recommended by the DCSF. Only 18% receive any kind of assessment of their needs.^{xxxi}



Action points

ACTION

Make background policy information available to team members.

RESOURCE

www.carers.org

www.carers.org/professionals



Developing your action plan

"The district nurses come on visits about my mother's ulcers but I feel invisible. No one says: 'How are you coping?' If you say: 'This is getting on top of me' then you get a few words of sympathy. The doctors also treat me like I am invisible, they come in and sort out mother then they just go."

Using this chapter will help you to:

Build on your existing strengths and good practice of understanding, identifying, supporting and referring carers.

Develop an action plan that is tailor-made to your practice.

Plan of action

Following are the key steps to developing your plan of action. Some of these will be more relevant to your practice than others, depending on your local needs, the other services you can draw on and the support you already have in place. Feel free to pick and choose those which are relevant to you..

- A. Finding and recognising carers
- B. Identifying a Carers Lead
- C. Providing information for carers
- D. Dealing with confidentiality issues
- E. Supporting carers within your practice
- F. Contacting carers' centres
- G. Helping carers access other services
- H. Planning for emergencies
- I. Identifying carers from communities that may be overlooked or hard to reach
- J. Supporting young carers
- K. What to do where no carer exists

A. Finding and recognising carers

The first step to making an impact on carers' health and contributions to patient care is to identify people in caring roles, or those who are likely to take on such roles. Carers rate recognition by professionals as one of their key wishes.

KEY OPPORTUNITIES FOR IDENTIFYING A CARER

- ✓ When a patient registers at the practice – they might be a carer or a care receiver.
- ✓ At the point of diagnosis or first concern for the patient.
- ✓ Home visits by GPs or community nurses.
- ✓ Ordinary appointments, particularly where someone accompanies the patient.
- ✓ Health checks or flu jabs and other practice nurse appointments.
- ✓ When someone orders or collects repeat prescriptions for another individual.
- ✓ At the point of hospital admission and discharge.

CARERS CAN ALSO BE IDENTIFIED PROACTIVELY THROUGH OTHER MEANS

- ✓ Searching practice records by condition, age, carer identified by patient.
- ✓ Encouraging carers to self identify using posters, leaflets, mailings or questionnaires, including those translated into local community languages other than English.
- ✓ Through partnerships with local carers support services, local community groups, Adult and Children Services Departments, housing services and associations.



- ✓ Home visits offered to those patients who appear to have a carer and talking to both together.
- ✓ Obtaining referral pads/cards for GPs from the local carer support service.

ONCE YOU HAVE IDENTIFIED A CARERS, YOU SHOULD:

- ✓ Record carer's identifying and contact details on patient records with the patient and carer's consent.
- ✓ Record the carer status on the carer's own records with the carer's consent.
- ✓ Consent to being registered should also be sought. It is important to obtain the consent of the patient being cared for so that the carer can have access to the information they need to help them to care effectively.



Carers Support Policy

B. Identifying a Carers Lead

The role of Carers Lead will vary from practice to practice, but experience shows that it can be easier to make improvements for carers with a lead in place. Please see below for a suggested Carers Lead role description.

The Carers Lead will:

- Be the main contact point between the practice and local Carers' Support Services.
- Keep colleagues up-to-date with carers support developments locally as well as national policy and entitlements at team meetings.
- Lead on monitoring numbers of registered carers and other action plan points.
- Ensure that carers satisfaction and feedback is collected with the aid of an annual survey.
- Complete the Self Assessment Checklist with the team on an annual basis.
- Act as a Carers' Champion and search opportunities for the practice to develop and improve its support for carers.

C. Providing information for carers

Information can be provided through the following means:

- Leaflets, posters and notice boards in the surgery – your local carers' centre will usually be able to provide you with resources and may even be able to take responsibility for keeping them stocked and up-to-date.
- Questionnaires or forms in the waiting room.
- Posters or signs asking carers to identify themselves and displaying the practice's Carers Support Policy, a sample of which is included at the end of this resource.

"I need to understand the treatment that he is receiving so that I can play my part in his recovery programme. What I do not need to know are the personal details of what takes place between him and the professionals concerned."

- Letters or mailings targeted at patients who are likely to be carers or care receivers.
- Translating written materials into the community languages, used by those in your practice population, other than English.

D. Dealing with confidentiality issues

"Her GP will not discuss her condition with me and I feel isolated from the situation, despite being her full time carer"

Professionals have a duty to respect the confidentiality of their patients and this can leave doctors anxious about talking to carers. Carers can end up feeling worried, ignored, isolated and ill-informed about the practical realities of the care they are trying to give. This can increase stress levels and contribute to the carer's own ill-health. It may even be dangerous for the carer or the person being cared for if they are involved in activities such as administering medication or responding to the behaviour of someone with a psychotic illness. Finding ways to share information appropriately can make a critical difference to the ability and confidence of a carer in their caring role.

Problems around confidentiality can be particularly acute in the mental health field. The Princess Royal Trust for Carers and The Royal College of Psychiatrists have published a joint leaflet on the issue which contains useful advice for professionals:
<http://www.rcpsych.ac.uk/PDF/Carersandconfidentiality.pdf>.

SIMPLE ACTIONS THAT GPs AND OTHER HEALTH PROFESSIONALS CAN TAKE TO MAKE A REAL DIFFERENCE

- Talk to patients routinely about the issues surrounding information-sharing and seek permission for carers to be given appropriate information about their care and treatment.
- Where a patient is reluctant for all information to be shared, talk through the consequences of this decision. There may be some aspects of a person's condition about which they are comfortable for information to be shared.
- Where the patient does not want any information given to their carer, ensure that there is general information on relevant health conditions available, for example leaflets on medical conditions or the effects of medication.
- Introduce agreements on information sharing to be recorded prominently in the patient's notes so that other members of the team are also aware of them.

E. Supporting carers within your practice

Carers may require extra support to attend their own appointments. They will also benefit from support in their caring roles. It is useful to have a written procedure for patients and staff which outlines the extra support that can be made available to patients identified as carers.

A sample Carers Support Policy is available at the end of this resource as well as on www.carers/professionals.org.

Carer Emergency Card

I provide substantial and regular care to another person

In the event of an incident please give this card to a police officer or health professional

F. Contacting carers' centres

If you have a local carers' centre, there may be a great deal that you can do in partnership with them in addition to the action points set out above. In many cases, you will be able to access free information and support from carers services, but this relies on stable funding for that service, often from the Primary Care Trust (PCT) who will need to hear from you that funding carers support is a real need from your practice's point of view. Where funding does not currently exist, you may wish to commission or part fund the establishment of a new service to work with a cluster of practices in your area – see section K of this chapter on Practice Based Commissioners.

There are a range of examples to draw on of partnerships between carers services and practices in chapter 5.

G. Helping carers access other services

Your practice will find that there is a range of support services for carers and their families in your area. All carers are entitled to a Local Authority Carer's Assessment. This is usually provided by Adult Services, and sometimes in partnership with a local third sector carers' centre. See chapter 5 for some of the key sources of support you could signpost or refer carers to.

H. Planning for emergencies

Emergency planning has been described as the "most valued least used" service. Carers are often very worried about what will happen if they are taken ill or if another emergency occurs. Who will care for the person they look after? Will anyone even realise that their relative has been left unsupported? Their well-being can be improved considerably by helping them to make contingency plans.

Emergency planning should be part of a Local Authority Carer's Assessment. Local carers' centres can also help. Many have "Emergency Card" schemes – where

the carer carries a card giving the phone number of a central control unit where an emergency plan is lodged.

Removing this worry can greatly reduce stress and at very little cost. Primary Care Teams can help by referring carers to a Local Authority Carer's Assessment or to their local carers' centre. Your practice may wish to develop a system which flags up the possible need for replacement care for when practice staff are aware that a carer has been taken ill.

I. Identifying carers from communities that may be overlooked or hard to reach

All people taking on a caring role are at increased risk of experiencing social exclusion, but those belonging to "hard to reach" communities are those who are least likely to be able to access appropriate information and support. Carers who are least likely to be able to access appropriate information and support are:

- Black and Minority Ethnic (BME)
- Lesbian, Gay, Bisexual and Transgender (LGBT)
- Mental health and substance misuse carers
- Disabled carers

Navigating Equality and Diversity – Guidance for the NHS April 2008 gives a single reference point for the key equality and diversity actions and deliverables as they apply to the NHS: www.nhsemployers.org/excellence/equality-diversity.cfm.

Useful action points include:

- Reviewing your equalities policy and how it is implemented.
- Identifying and addressing your practice teams' training needs.
- Making links with community groups from those local communities your practice currently finds hard to reach.

“There are two GPs I normally go and see. One's quite a cold person but the other is very supportive so I always try and see him.”

Carer of husband with terminal cancer



BRITISH ETHNIC MINORITIES (BME)

Research undertaken by the Black Carers and Carers Workers Network demonstrates that carers from BME communities are more likely to be struggling to combine paid work and caring than their white British counterparts and more likely to be struggling to make ends meet. It also indicates that mistaken ideas about extended family support in BME communities act as a barrier to carers being offered services.

Cultural awareness training helps practice staff feel more

confident in offering appropriate support. This training might explore the attitudes of different communities to health conditions and caring, but should also look at the dangers of assuming that individual patients share the attitudes commonly ascribed to their communities.

Translation services help the communication of information. Different cultures use different explanations for the concept of “carer” and using a word for word translation is often unhelpful. Translation services will help convey all the information relevant to the carer role.

An independent interpreter (as opposed to a member of a carer or patient’s family or a community spokesperson) can address confidentiality issues for carers. Young carers are often called upon to translate where their parents do not speak English. It is not appropriate for children to be used in this role.

LESBIAN, GAY, BISEXUAL AND TRANSGENDER (LGBT)

A survey by lesbian and gay community groups in Brighton and Hove found that half the town’s lesbians and gay men were not “out” to their GPs and also that GPs’ understanding of the health needs of lesbians and gay men was often limited by assumptions about their (hetero)sexuality.

In Brighton and Hove, the local lesbian and gay community worked in partnership with the health authority in establishing ‘The Lesbian and Gay Friendly GP Practice Scheme’, where all practice staff receive training in a range of issues.

MENTAL HEALTH AND SUBSTANCE MISUSE CARERS

These groups of carers are particularly likely to be hidden and overlooked, due to the stigma attached to these conditions and the invisibility of the care they provide, which may be largely focused on emotional

support and feeling responsible for another individual's safety. The health impacts of these kinds of caring roles can be just as great as that of other caring roles. These groups of carers may be reluctant to talk about the impact of caring, particularly in front of the person they care for, who in turn may not be aware of the full impact of their care needs on their families. In some areas, as well as generic carers services, there may be family groups specific to substance misuse problems.

If you have not already done so, see section D of this chapter when talking about mental health.

J. Supporting young carers

A young carer's health can be severely affected by:

- Caring on a daily basis and sometimes through the night.
- Physical tasks such as repeatedly lifting a heavy adult or sibling.
- Emotional impact, anxiety, stress, depression and sense of isolation.
- Poor diet.
- Lack of opportunity to socialise and take exercise.
- Leading unhealthy and isolated lives.

Young carers learn practical and caring skills at an early age and are often seen as “copers”. However, it is important to remember that they are children with the same emotional and health needs as others their age.

GPs may be the first person that a family turns to for help so always think “young carer” when seeing a patient who has care needs and is a parent. Remember children help care for disabled and ill siblings too. Timely intervention or signposting could prevent a child undertaking inappropriate levels of care which have an impact on their own health and wellbeing.

Asking the following questions may help in identifying caring responsibilities and knowing how best to signpost the family in the direction of help.

- Who helps to care for the person at home?
- What effect do the health conditions and personal care needs have on the family?
- Is there a child or young person helping to provide care?
- How does this affect the child?
- What additional support or signposting is needed to obtain more services for the person needing care?
- Is any direct support needed to meet the child's own physical or emotional health?

For your support access the Whole Family Pathway and GPs pack at www.youngcarer.com.

A young carers service is available in most areas. The Princess Royal Trust for Carers has the largest network with 83 Young Carers Services supporting 15,500 young carers through advice, mentoring, clubs, holidays and whole family support. The Trust also offers young carers and their families an online service which is available 365 days a year at www.youngcarers.net. This provides information, email support and chat sessions and is staffed by specialist youth workers. Where there is no young carers service, consider contacting the School Nurse to liaise with family and other agencies. A full list of projects is available at www.youngcarer.com.

K. What to do where no carers' centre exists

Many areas will have a specialist carers service of some kind, however in some areas the service needed to meet the needs you are likely to identify through using this resource will not yet exist. In these cases, many PCTs and Practice Based Commissioners (PBCs) practices have decided to commission new services, as some of



the inspiring examples of partnerships included in this resource illustrate. The NHS Operating Framework 2008-09 says: “We expect PCTs to support PBCs in using their financial flexibility to make the simple changes that improve matters for patients – such as arranging for a replacement carer, so that an elderly person does not end up in hospital when their carer has a routine operation.” (paragraph 3.10).

Commissioners may wish to:

- Work with Local Involvement Networks (LInKs) to consult with carers and other stakeholders.
- Make use of the Joint Strategic Needs Assessment process alongside your council and Local Strategic Partnership, to assess the level of need.
- Contact local carers and condition specific services and third sector organisations to map current provision and gauge the potential of the current provider market.
- Contact The Princess Royal Trust for Carers for advice, support and good practice models at www.carers.org/professionals.

Airedale PCT has commissioned a comprehensive service for carers in general practices from its local Carers Resource. The team comprises a Development Worker, Information Officer, three Support Officers and an Activities Coordinator, providing ongoing support to an average of 270 carers in each six-month period, as well as information to many more.

DISCUSSION POINTS FOR YOU AND YOUR TEAM

- What needs to be included in your action plan?
- Who will be allocated as your Carers Lead so as to develop and implement your action plan.
- Discuss appropriate time frame and resources.

Action and discussion points

ACTION	RESOURCE
Raise awareness within your team.	Refer to chapters 1 to 3, or raise awareness in the form of informal training by the Carers Lead.
Identify a Carers Lead to take the work forward.	See section B of this chapter: Identifying a Carers Lead.
Pool knowledge and skills.	Identify a Carers' Lead to consult with colleagues and lead team meeting discussion.
Develop your version of the policy in partnership with staff and review it regularly at team meetings.	Refer to chapter 3.
Identify your existing good practice.	Complete the Self Assessment Checklist to identify strengths and gaps to feed back to the team.
Develop an action plan according to your local needs, the services you can draw on and the support that you already have in place.	See suggestions at the beginning of this chapter.
Identify and reach Black and Minority Ethnic (BME) carers within your practice.	Refer to section I of this chapter as well as research and develop, where appropriate, cultural awareness training, translation services and the use of an independent interpreter.
Identify and reach Lesbian, Gay, Bisexual and Transgender (LGBT).	Contact the National Association for Voluntary and Community Action for advice on engaging with appropriate community groups.
Identify and reach young carers	<p>Use display on waiting room notice boards to encourage families to come forward. See www.youngcarer.com for examples.</p> <p>Where an adult is diagnosed with a long term condition, practice staff should routinely ask:</p> <ul style="list-style-type: none"> ■ Do you have children? ■ How can we support you as a parent? <p>A young carer may be helping to look after a parent or sibling. Where practice staff believe a child may be in a caring role, consider:</p> <ol style="list-style-type: none"> 1. Asking the following questions. <ul style="list-style-type: none"> ■ Who helps to care for the person at home? ■ What effect do the health conditions and personal care needs have on the family? ■ Is there a child or young person helping to provide care? ■ How does this affect the child? ■ What additional support or signposting is needed to obtain more services for the person needing care? ■ Is any direct support needed to meet the child's own physical or emotional health? 2. Contacting your local specialist young carers service and informing the family of what is available or visit www.youngcarers.net or www.youngcarer.com.
Identify and reach young carers	3. Signposting the family to relevant services if you are concerned the child may be at risk by consulting the safeguarding procedures within the PCT– if in doubt, consult with the Practice Manager or the Duty Team in Children's Services.
Show evidence of your good practice and monitor your progress.	Use the Self Assessment Checklist.



What examples are there of General Practice teams working to support carers?

"I've been struggling to look after my son for years and then I change doctor and go and see my new GP and this kind lady doctor asks me how I was coping as a carer and I just burst into tears. And now she's referred me to you which is wonderful!"

Using this chapter will help you to:

See best practice examples of how other practices have worked to support carers

Is your practice using a model that works well to support carers? Let people know about it. Email info@carers.org to share your good work across the country.

Practice-based carers support in West Sussex

The Carers Development Worker (Primary and Community Care) project at The Princess Royal Trust Worthing & District Carers Liaison Service has had a dramatic effect on the numbers of carers identified by GP practices, with some increasing their numbers of registered and supported carers by many times since 2004. One full time equivalent Carers Development Worker based at the service works with 37 GP practices.

The project:

- Identifies a link person in each GP practice.
- Completes an annual Monitoring Tool.
- Uses an Action Plan for task completion.
- Provides Carer Awareness training and information/support for all GP staff.
- Promotes healthy living practices at carers' events.
- Ensures that GPs work to the GMS contract (Management Indicator 9).

For more information, please contact via www.carerswsx.org.uk.

Networking Primary Care Carers Champions in Cheshire and Greenwich

As part of its Carers Strategy, Western Cheshire PCT has asked each GP practice to identify a Carer Link from their staff. These links will act as the main support point for carers, keep practice information up-to-date, link with other services and meet with each other with PCT support. A group including carers and carers' organisations steers the project.

For more information, please contact Tom Livingston at Chester Crossroads on chester@crossroads.org.uk

Greenwich Carers' Centre (The Princess Royal Trust for Carers) has developed a carers support protocol for local GPs which the PCT promoted to all their surgeries. The protocol includes leaflets and information posters. The Centre is now developing a Carers Champion E-group for local primary care partners. Each surgery will nominate a Carers Champion who will receive regular updates from the centre, share good practice and represent the surgery at carer forums organised by the local council and the carers' centre throughout the year.

For more information, please contact CEO Sue Mitchell on sue.mitchell@greenwichcarerscentre.org.

Hospital based resources for carers in East Sussex

The Princess Royal Trust for Carers member Care for the Carers and East Sussex hospitals NHS Trust have produced a range of resources for supporting carers, including a Good Practice Guide for hospital staff covering information such as knowledge-sharing, a



Carers Information Leaflet and a Care Passport, allowing carers to help the cared-for person express their care needs and let staff know they can share information with the carer.

For more information and relevant contact details, please see www.carers.org/local/south-east/eastbourne/ for more and relevant contact details.

Macmillan Crossroads Cancer and Palliative Care Service in Huntingdonshire

Macmillan Crossroads and Palliative Care Service is a partnership to support carers and people affected by cancer through their journey with cancer. A Steering Group of carers, health and social care providers and commissioners, as well as representatives from Macmillan Cancer Support and Crossroads, oversees the service.

This new specialist service aims to:

- Improve the quality of life of both carer and person with care needs.
- Reduce the number of admissions to hospital and hospice.
- Reduce the length of stays in hospital.

It is hoped that savings made by reducing time spent in hospital, reducing emergency admissions and avoiding admission to hospital will make the business case for the PCT to contribute to funding during and at the end of the Macmillan funding period.

Safe handling project in Birmingham

Research carried out by the Carers Support Initiative 'Your Health, Who Cares?' report of June 2001, found that over 50% of the carers who responded to the survey indicated that back pain was a health issue that

affected them. Birmingham Crossroads provides carers with training in safer lifting and handling in carers' own homes and in group training sessions as well as first aid training. Outreach work allows the service to identify where safe handling equipment in the home is not being used and facilitate a tailored training session for the carer. Home-based training is useful for carers who cannot attend groups, or who work. The service maintains an efficient referral pathway to occupational therapy teams in the area and facilitates safe and effective discharge from hospital through training carers.

Carers receive the training free through an open referral system. The service is also sold to individuals in receipt of direct payments so that their personal assistants can be trained. A steering group includes representatives from funders, occupational therapists and carers. The service has produced a training video. The service is staffed by a full time manager and seven part time trainers.

For more information, please contact Barbara Rudge at West Birmingham Crossroads on barbarawbcrossroads@yahoo.co.uk.

Carers emergency planning and respite in Sefton and Merton

Sefton Council commissions The Princess Royal Trust for Carers Sefton Carers' Centre to provide the Carers' Emergency Respite Team (CERT). The service provides home-based respite support to carers in crisis or emergency situations for a period of up to 48 hours. During the 48-hour period the team can provide a series of 'pop in' calls or, if necessary, will arrange a total move in to support the person being cared for. An important feature of the service is the advanced care planning which is carried out when a carer registers with the service, so that everyone in the team is clear about the individual's needs and support required in an emergency. The care plan includes an exit strategy,

which considers how support will continue to be provided beyond the 48-hour period if this is required. Typically the exit strategy will include the carer's network of support, and if this is limited, the service links and the local authority social services department.

For more information, please contact Liz Williams on help@carers.sefton.gov.uk.

The London Borough of Merton (LBM) has provided a partnership-based solution to deliver an emergency response service. LBM commission Carers Support Merton (The Princess Royal Trust for Carers), Mascott (telecare services) and Merton Crossroads – Caring For Carers, to provide the scheme. Initial contact to the scheme is via Carers Support Merton who provides the carer's alert card. This process initiates the essential planning element required for any emergency response. The card is carried by the carer and gives the 24-hour telephone number run by Mascott. In an emergency anyone using the card can contact Mascott who alert the person nominated by the carer to provide care in an emergency situation. The nominated person can be a relative, friend or neighbour. However not all carers have a nominated carer or one that can attend immediately or for the whole time that the emergency exists. Merton Crossroads are therefore commissioned to provide care for the cared-for in the short term during the emergency until more permanent arrangements can be made. This short term emergency home-based care is provided for periods of up to 48 hours and during this time long term arrangements can be developed if necessary. Merton Crossroads provides an on call care support worker 24/7 who can, in an emergency, provide pop in calls, substantial care hours or a total move in for a period of 48 hours. The home-based service is designed to either replace the carer in total or support the nominated person in their caring role. The service is an extension of the respite care service already provided by Merton Crossroads and supports carers who are unable to continue in their normal caring role due to sudden injury, illness or unplanned hospital admission.

For more information, please contact Harsha Ganatra on harsha.ganatra@carerssupportmerton.org.uk.

Reducing the risk of fire in Suffolk

Suffolk Family Carers (The Princess Royal Trust for Carers) works in partnership with Suffolk Fire and Rescue Service to provide home fire safety checks for family carers and vulnerable people so they can discuss how to prevent fire in the home. The Fire and Carers Together (FACT) scheme is a free service which recognises that some people may have particular difficulty in leaving the home in the event of a fire. FACT also offers an emergency database within the Control and Command Room to identify households registered on the scheme. For more information, please see www.suffolkfamilycarers.org.

The caring café for dementia carers in Richmond upon Thames

Richmond Crossroads, with support from Alzheimer's Society, Big Lottery and others, provides carers and people affected by dementia the opportunity to socialise in a friendly and welcoming environment, supported by a skilled staff team. The café is open every Saturday from 11 am to 4 pm in the centre of Richmond on premises given free by Richmond Age Concern and provides respite, support, social opportunities and activities to tackle isolation. Transport is provided when needed.

Up to ten people with dementia can use the café whilst their carer goes into town for up to two hours, but most carers wish to remain with the person they care for. Workers, including a part time coordinator, four café support workers, receptionist, Dementia Advice Worker and volunteers receive dementia care, personal care, moving and handling and other training.

For more information, please contact Eleanor Willett at Richmond Crossroads on richmonduponthames@crossroads.org.uk.



Surgery Link in Gloucester

'Surgery Link' provides trained team members to visit Surgeries once every four to six weeks. The aims of the service are:

- To raise awareness of carers services among health professionals, and increase referrals.
- To raise awareness with patients.
- To provide a service tailored to the individual practice's requirements.

Currently the team has links with 56 surgeries around the county. Enthusiasm for contact about carers' issues varies with many nurses, practice staff and receptionists ahead of their GPs on this issue. The service includes regular personal delivery of business card style flyers, carer notice boards and A4 folders of information to practice managers and visits to speak to practice teams. Most surgeries nominate a team member, often a nurse, as their Carers Lead. One surgery operates a carers' group in partnership with a nearby care home that can support cared-for people whilst the carers meet. A nominated receptionist in one surgery phones all carers aged over 65 on a monthly basis. Carers' outreach workers approached patients waiting for flu jabs with information in some surgeries and some have monthly carer clinics with both practice and carers' centre staff present.

For more information, please contact Roger Hare at Carers Gloucestershire at RHare@gloscarers.org.uk.

Use of electronic records in Lewisham

One of the GP practices in the London Borough of Lewisham has introduced an electronic health record system that allows patients to register to access their own records remotely online. The local Lewisham Carers' Centre, who form part of The Princess Royal Trust for Carers network, has agreed with the practice that there should be a website link from the record site

to the centre's site so that there is easy access to information for carers.

For more information, please contact cathy@carerslewisham.org.uk.

Specialist carer support within GP practices in North Yorkshire

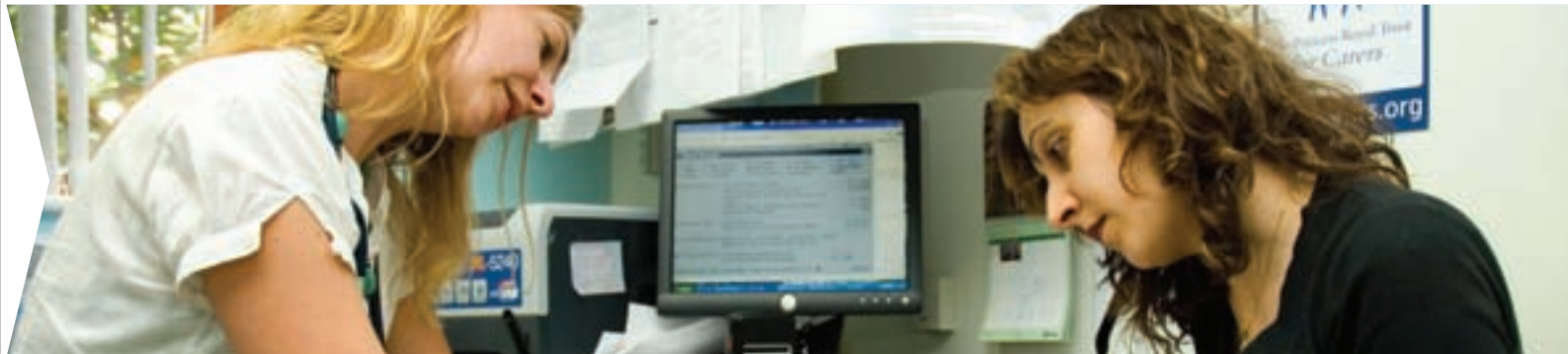
In the 1990s, The Carers' Resource (Harrogate, Craven and Airedale) ran a number of one-year pilots, providing a Carers Support Officer 20-25 hours per week to single general practices, backed up by a comprehensive information service. Since then, Carer Support Officers (from five to 20 hours per week) have been embedded in a number of local practices, with practice agreements to ensure effective cooperation. Additional PCT contracts include:

- Providing focussed carer services with six Memory Clinics whilst consultants in psychiatry (elderly medicine) and psychologists investigate dementia sufferer's situation.
- Providing carer support in palliative care cases.
- Carer Support Officers linked with Single Assessment Process teams to ensure carers' needs are addressed properly through this emerging new system.

For more information, please contact Anne Smyth at director@carersresource.org.

Hospital-based carer support in North Yorkshire

The Carers' Resource (Harrogate, Craven and Airedale) has developed a number of hospital-based programmes, including a specialist Carer Development Worker for one local hospital and provision in other hospitals linking the organisation with hospital admissions teams, discharge



teams, community rehab teams, child development centres, cancer teams etc. In some wards, families visiting patients are directly referred by nursing staff to the carers service.

The Carers' Resource has analysed the situations of more than 7,300 carers who have received sustained, ongoing one-to-one support through this work. The service also assists in training medical students and on the curriculum development team of a university departments of health studies.

For more information, please contact Anne Smyth on director@carersresource.org.

Partnerships for Older People Projects (POPPs) in North Yorkshire and Somerset

The Carers' Resource (Harrogate, Craven and Airedale) had two of the first pilot POPPS contracts to prevent admission to hospital by providing enhanced carer support and by providing older person peer mentoring for vulnerable elderly people living on their own. These services are now main-streamed.

For more information, please contact Anne Smyth at director@carersresource.org.

North Somerset Crossroads has developed a scheme to assist carers aged 50 and over to access services of their choice. They have produced a 'menu' to give older carers ideas of the services they might like, using a budget allocated for each carer and funded by POPP to design the service needed by the individual to help them in continue to care. The menu includes day trips, night sitting, gardening, personal development courses such as cookery and relaxation techniques, courses relevant to caring such as moving and handling, complimentary therapies and help to access short term nursing care.

For more information, please contact

carescheme@nscrossroads.org.uk.

PCT and council partnerships in Sandwell

The Princess Royal Trust Sandwell Carers Centre has pioneered several effective partnerships with the PCT and the council. There is a Carers Champion, who is a GP, on the Professional Executive committee of the PCT. The centre works with GP practices to ensure they have adequate carers information in place. One practice has started a carers group, with agendas set by the over 20 carers who attend. As a result of the carers' input, the practice has a daily "carer's appointment" accessible in an emergency for carers who want to see a doctor. The centre is now developing Gold, Silver and Bronze carer support and involvement awards for practices.

For more information, please contact cares.sandwell@btinternet.com.

HIV support in Lanarkshire

Princess Royal Trust Lanarkshire Carers Centre works with Terrence Higgins Trust (THT) and NHS Lanarkshire Blood Borne Virus Network, who part fund their support for carers affected by HIV and other blood borne viruses. This includes a part time bilingual support worker working with BME carers affected by blood-borne viruses. The centre and THT, share information, hold joint meetings and support groups, and provide carers workers with Lesbian, Gay, Bisexual and Transgender (LGBT) training.

For more information, please contact Lesley Fishleigh at Lesley.Fishleigh@prtlcc.org.uk.



Where to find more information
and support for your work
with carers

“The doctor used to bring my notes as well when he made a home visit.”

National organisations and websites

Action for Carers in Employment

www.carersuk.org/Employersforcarers/ACENational

Carers and confidentiality

www.rcpsych.ac.uk/PDF/Carersandconfidentiality.pdf

Carers UK

www.carersuk.org

Citizens Advice

www.citizensadvice.org.uk

Crossroads Caring for Carers

www.crossroads.org.uk

DirectGov

www.direct.gov.uk

End of Life Care Strategy - promoting high quality care for all adults at the end of life

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277

Equality and Diversity

www.nhsemployers.org/excellence/equality-diversity.cfm

Experts Patients Programme Community Interest Company

www.expertpatients.co.uk

Jobcentre plus

www.jobcentreplus.gov.uk

Local Involvement Networks (LINKs)

www.dh.gov.uk/en/Managingyourorganisation/PatientAndPublicinvolvement/dh_076366

National Association for Voluntary and Community Action

www.nacvs.org.uk/cvsdir

New Deal for Carers

www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Carers/NewDealforCarers/index.htm

NHS Next Stage Review final report

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825

NHS

www.nhs.uk

Partners in care

www.partnersincareny.org/a_index.html

Royal College of General Practitioners

www.rcgp.org.uk

The Princess Royal Trust for Carers

www.carers.org

The Princess Royal Trust for Carers Professionals website

www.carers.org/professionals

The Princess Royal Trust for Carers website for young carers

www.youngcarers.net

The Royal College of Psychiatrists

www.rcpsych.ac.uk

Young Carers Initiative

www.youngcarer.com



Adult Services	Community care assessments and support for the person cared-for. Carers' assessments for carers.	Via the council's enquiries line or the local carers' centre.
Advocacy	Help for carers to navigate through systems to get the support they need.	May be offered by local carers services or by specialist advocacy services.
Benefits advice	Help in getting the benefits to which the family is entitled.	See www.citizensadvice.org.uk to find nearest Citizens Advice Bureau. Or, contact your local carers' centre.
Breaks and respite services	Time off to allow carers some respite thus reducing stress levels and improving well-being.	See www.crossroads.org.uk for your nearest Crossroads Caring for Carers service. Carers' centres will be able to signpost carers to breaks and respite services. Carers can access breaks, sometimes in the form of small grants, via a statutory Carer's Assessment.
Carers' centre	Information, support, advocacy, access to respite breaks and many other services.	See www.carers.org for your local carers' centre. Most carers' centres will accept telephone referrals with the consent of the carer and many provide referral pads/cards for use in practices.
Children services	Support for children and parents.	Via the council's enquiries line or the local young carers service.

Helping carers access other services

Community transport	Subsidised transport.	Contact your local carers' centre or see www.nacvs.org.uk/cvsdir for your local voluntary and community services.
Counselling and emotional support		May be offered by local carers services or by specialist counselling services.
Expert Carers Programme	Courses helping carers to feel more informed, skilled and confident about their caring role.	See www.expertpatients.co.uk or contact your local carers' centre.
Help staying in or accessing employment	Specialised information and support about work related issues.	Contact your local carers' centre or trade union. See www.jobcentreplus.gov.uk for your nearest JobCentrePlus.
Local community groups	Can include carers groups and/or other support, campaigning or social groups of people identifying themselves as belonging to particular communities of interest for example BME, LGBT or disabled.	See http://www.navca.org.uk/cvsdir for a directory of voluntary and community services.
National carers' advice line	Information and access to other services.	See www.nhs.uk Helpline number is to be confirmed in January 2009.
Online support and advice	Information and support.	See www.carers.org . www.youngcarers.net – Young carers support service staffed by specialist youth workers seven days per week. www.carersuk.org



Sharing and celebrating your support for carers

“I had a phone call out of the blue from the GP to check up if everything was ok.”

Using this chapter will help you to:

Use the Self Assessment checklist.

Contribute your good practice example to this guide

The Self Assessment Checklist is intended to help you keep track of your progress and to be able to evidence your work. It links the good practice suggested in this resource to the QOF. We suggest that you begin by using the Checklist with your team to help gain a sense of where your current strengths and challenges lie and then use the Checklist again, having worked through some of the suggested actions, to monitor your progress.

Contribute your good practice example to this guide

We would like this to be a living resource and for that we need your help! We would be very grateful for your contributions of good practice, lessons learned and sources of information. Please complete the template at [LINK](#)

We will update the online version of this resource regularly, including new examples of good practice, so contributing will be a way of celebrating and sharing your achievements nationally.

Please email your examples of good practice to info@carers.org.

Feedback

We would welcome any comments you have on this resource. Please email info@carers.org with your thoughts on the guide's usefulness.

The Criteria

Services for carers Practices recognise that carers are key partners in the provision of care	Not met at all	Needs improvement	Fully achieved	References
1. ACCESSIBILITY				
a) Carers are able to obtain the service of the team at appropriate time and delay without undue delay.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Evidenced by:				
b) Practices take account of the needs and responsibilities of carers, as well as patients, when making decisions about home visits and appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	QPA QTD PrAcc1.3G SBH C17 SBH D11
Evidenced by:				
c) In a medical emergency involving a carer, practice systems must ensure the needs of both the carer and carer-for are addressed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	QPA QTD PrAcc1.3G SBH C17 SBH D11
Evidenced by:				
d) Practices ensure discharge from hospital procedures recognise carers as key partners in discharge planning and continuity of care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	QPA QTD
Evidenced by:				

2. AVAILABILITY OF INFORMATION				
a) The team communicates openly with carers and actively encourages their involvement in decisions affecting the patient and carer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	QTD SBH C17 SBHD9
Evidenced by:				

b) The practice supports carers as key partners by providing leaflets that outline carers' rights, responsibilities and the services provided for carers by the practice.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	QPA QTD SBH C16
Evidenced by:				

c) The practice has up-to-date information for carers on national and local support services across a range of specialist areas.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	QTD SBHC16
Evidenced by:				

3. MANAGEMENT OF CHRONIC ILLNESS				
a) The team supports carers of patients with long term conditions to manage their care at home effectively and reduce the need for hospital admissions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	QPA QTD PrAcc6.1E PrAcc6.2G PrAcc6.3Q SBH D10 SBH D11
Evidenced by:				

b) The team supports carers to manage their own health needs and offers an annual health check.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	QPA QTD
Evidenced by:				

c) The team ensures that carers are involved in planning the care for people with multiple problems including high risk patients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	QPA QTD PrAcc6.1E PrAcc6.2G PrAcc6.3Q
Evidenced by:				

4. MEDICINES MANAGEMENT				
a) The team involves carers in the appropriate use of medicines by ensuring that they are informed about administration as well as benefits and significant side effects.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	QPA QTD PrAcc3.2G SBH C4d
Evidenced by:				

b) Medication reviews take into account the carer's understanding of the use of medication, significant side effects, appropriate monitoring and review of the need for continued treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	QPA QTD PrAcc3.2G SBH D1
Evidenced by:				

5. REFERRALS

a) Carers are referred to team members or other statutory and voluntary agencies where appropriate, e.g. respite care, local carers' centre, OT, social services.

QPA
QTD

Evidenced by:

b) Where appropriate, carers are copied into correspondence in relation to referrals.

QPA
QTD

Evidenced by:

6 PREVENTATIVE CARE AND HEALTH PROMOTION

a) The needs of carers are addressed in all areas of preventative care and health promotion.

QPA
QTD
SBH C6
SBH D2

Evidenced by:

b) Carers are offered influenza vaccinations annually as part of the high priority groups.

Evidenced by:

7 CHILDREN'S HEALTH				
a) The practice has a protocol for identifying and supporting children who may need carers and a system for making referrals to appropriate statutory and voluntary services for support.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	QPA QTD SBH C2 QOFCHS1
Evidenced by:				

8 MENTAL HEALTH SERVICES				
a) The number of patients on the register who have a comprehensive care plan documented in the records agreed between individuals, their family and/or carers as appropriate, is at least 50%.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	QPA QTD PrAcc3.2G SBH C4dQPA QTD SBH C2 QOFCHS1
Evidenced by:				

b) In developing care pathways for patients with mental health problems or severe mental illness the team must address the needs and involvement of carers in plans for shared care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	QTD
Evidenced by:				

c) For patients who abuse drugs or alcohol, the team has a policy for assessment, management and referral which includes the needs of carers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	QTD
Evidenced by:				

9 CONTINUED CARE IN THE HOME

a) Patients requiring care in their home are assessed by members of the team and care is planned with them and their careers to meet their needs and wishes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	QPA QTD PrAcc3.2G SBH C4dQPA QTD SBH C2 QOFCHS1
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Evidenced by:

b) Patients and their carers are offered information and choice about the care they receive.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	QTD PrAcc11.3G SBH C18
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Evidenced by:

c) Team members regularly review together the care they are providing, assessing the impact on the team, the carer and the patient.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	QTD PrAcc11.7Q
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Evidenced by:

d) The team has a protocol for the identification of carers and a mechanism for the referral of carers who want a social services assessment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	QPA PrAcc11.2G QOF MAN9
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Evidenced by:

9 CONTINUED CARE IN THE HOME				
e) The team works together and with other agencies to provide end of life and palliative care which meets the needs of patients and recognises the care as a key partner in decision making.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	QTD PrAcc11.4G
Evidenced by:				

f) The team ensures that bereaved carers and relatives receive the support they require.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	QTD PrAcc11.8Q GSF
Evidenced by:				

10 PALLIATIVE CARE				
a) The practice has a complete register available of all patients in need of palliative care/support and their carers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	QPA QOF PC1 QMAS
Evidenced by:				

b) The practice has regular (at least 3 monthly) multidisciplinary case review meetings that include the health and support needs of carers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	QPA QOF PC2 QMAS
Evidenced by:				

Abbreviations

GSF	Gold Standards Framework (Palliative Care) a practice-based system to improve the organisation and quality of care for patients in their last stages of life in the community.
PrAcc	RGCP Northern Ireland Practice Accreditation Programme developed from the RGCP Scotland Practice Accreditation Scheme, a professionally led multidisciplinary programme supporting clinical governance and enhanced patient care through a team-based approach.
QMAS	Quality Management Analysis System. A national IT system which gives GP practices and PCOs objective evidence and feedback on quality of care delivered to patients.
QOF	Quality and Outcomes Framework. The Quality and Outcomes Framework (QOF) measures achievement in primary care against evidence-based indicators. The indicators cover four 'domains': clinical, organisational, patient experience and additional services. The QOF became part of the new voluntary part of the General Medical Services (GMS) and of the Personal Medical Services (PMS_ contracts on 1 April 2004. The QOF is a UK-wide initiative and although participation in the scheme is voluntary, take up is extremely high for GMS and PMS practices (over 95%) and achievement of QOF thresholds results in bonus payments.
QPA	RGCP Quality Practice Award. QPA is a quality assurance process undertaken by practices, which recognises a high standard of quality patient care delivered by every member of the practice team. Each practice is required to submit a portfolio of written evidence set against 23 sets of criteria.
QTD	RGCP Quality Team Development programme is a team appraisal with a comprehensive evaluation of clinical governance processes in a practice. It is designed to support general practices in improving the quality of their services.
RGCP	Royal College of General Practitioners
SBH	Standards for Better Health. This document was published formally as an integral part of National Standards, Local Action (July 2004) which set out the framework for all NHS organisations and social service authorities to use in planning over the next three financial years.
SBH C	A core criterion in the SBH standards framework.
SBH D	A developmental criterion in the SBH standards framework.

Supporting Carers: An action guide for general practitioners and their teams

Carers in Employment Charter

In this organisation we recognise and value the contribution made by carers to our society and therefore we acknowledge the needs and difficulties faced by our employees who are carers and the impact this has on their working lives. We will seek to establish and monitor policies and practices to enable employees to balance their caring responsibilities with their workplace role.

If you would like further information contact:

All enquiries will be treated in the strictest confidence.

We define a carer as:

“Someone who looks after a relative or friend who cannot manage without help because of illness, frailty or disability.”

We hold to the following principles:

1. We will foster an understanding attitude at all levels in the organisation and promote the benefits of “carer friendly” employment.
2. We are committed to providing information to carers so that they may be aware of the help and support available from this organisation and a variety of other support agencies.
3. We are committed to developing flexible approaches to work in order to assist carers to remain in their job role while caring for others.
4. We recognise and accept that supervisors and managers play an important part in the application of these charter principles.

This charter was developed by The Princess Royal Trust Sunderland Carers Centre and partners.

Supporting Carers: An action guide for general practitioners and their teams

Carers Support Policy

Carers are people who, without payment, provide help and support to a family member, friend or neighbour who cannot manage on their own due to physical or mental illness, disability, substance misuse or frailty brought on by old age. Caring roles can include administering medication, lifting and handling, personal or emotional care.

If you are a carer, you might find it difficult to access our services without extra support. If you identify yourself as a carer, our staff will try to offer you:

1. Home visits and/or telephone appointments if caring responsibilities mean you cannot leave the person you care for at home or bring them with you to the surgery.
2. Flexibility or priority on appointment times where possible.
3. Support for the person you care for in the waiting room or a private area if you need to bring them to the surgery but would like an appointment in private.
4. Information about local carers support services which may be able to arrange transport and/or sitting services to help you leave home to attend surgery.
5. Telephone ordering for prescriptions where possible.
6. An annual health check and a flu jab.
7. Information about your right to a Carers' Assessment of your own needs as a carer.
8. Advice on safer lifting and other aspects of providing care such as medication.
9. Discussing with you what you would like us to do in the event of you or the person you care for having a medical or other emergency.

In some cases caring roles are full time and very demanding. We would like to support you in your caring role where we can. We will avoid making assumptions about the amount of care you wish to take on. Caring should not be at the expense of your own health and wellbeing. Please tell us how your caring role is affecting you and if you have any support needs.

We will try to help you by:

- Respecting your privacy and confidentiality and conducting conversations of a personal nature in private.
- Discussing the benefits of appropriate information sharing with patients who need or may in future need care from a relative or friend.
- Providing you with information about the condition and needs of the person you care for, such as the effects of medication, where that person gives consent.
- Always listening to and respecting the information you give us about your caring role and the needs of the person you care for.
- Providing you with general information about health conditions when you ask for it when we do not have consent from the person you care for to share their personal information.

Our Carers Lead is:

Please contact them if you have any queries about our support for carers - they will be happy to help and treat the conversation in strictest confidence.

This policy has been developed by The Princess Royal Trust for Carers and Royal College of General Practitioners



Contributors to be thanked

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References

- i *State of Social Care 05-06* report. CSCI. London. 2006.
- ii UK Census 2001
- iii HSA/The Princess Royal Trust for Carers research 2001.
- iv General Household Survey. 2000.
- v *Real change, not short change: Time to deliver for carers*, Carers UK, 2007.
- vi National Carers Strategy Consultation; Submission from CLASP Carers Centre in Leicestershire. 2007.
- vii *ibid*
- viii Keeley B, Clarke M. *Carers speak out project: report on findings and recommendations*. London: The Princess Royal Trust for Carers, 2002.
- ix *Young Carers in the UK The 2004 Report*, Dearden, C and Becker, S. Loughborough University Young carers research group. 2004.
- x National Statistics. *Health symptoms felt by informal carers: by number of hours spent caring, 2000/01: social trends 33*. London: National Statistics, 2003.
- xi Horsley S, Barrow S, Gent N, Astbury J. Informal care and psychiatric morbidity. *J Pub Health Med* 1998;20:180-5.
- xii Keeley B, Clarke M. *Carers speak out project: report on findings and recommendations*. London: The Princess Royal Trust for Carers, 2002.
- xiii Keeley B, Clarke M. *Carers speak out project: report on findings and recommendations*. London: The Princess Royal Trust for Carers, 2002
- xiv Yeandle, Sue 2007 Carers UK and the University of Leeds.
- xv Derived from the UK Census 2001, calculated in BMJ online learning module: *Supporting Carers*.
- xvi UK Census 2001
- xvii *Alcohol Harm Reduction Strategy for England*, Home Office. 2004.
- xviii *Women's Mental Health: Into the Mainstream. Strategic Development of Mental Health Care for Women*. London: Department of Health. 2002.
- xix *Hidden Harm*, Advisory Council on Misuse of Drugs. Home Office. 2003.
- xx UK Census 2001
- xxi *Real change, not short change: Time to deliver for carers*. Carers UK. 2007
- xxii *ibid*
- xxiii *Operational plans 2008/09 - 2010/11 (Implementing the 2008/09 Operating Framework) National Planning Guidance and "vital signs"*
- xxiv National Stroke Strategy DH 2007
- xxv Community Care (Delayed Discharges, etc) Act 2003; Single Assessment Process guidelines, outlined in the NSF for Older People 2001
- xxvi *The Local Government and Public Involvement in Health Act (2007); Delivering health and well-being in partnership: The crucial role of the new local performance framework* (DH/CLG 2008)
- xxvii Statutory guidance to the Community Care (Delayed Discharges, etc) Act 2003, page 37
- xxviii Single Assessment Process guidelines, outlined in the NSF for Older People 2001, page 27
- xxix *Ibid* page 16
- xxx Eurostat 1997
- xxxi Cawson et al, 2000, for the NSPCC
- xxxii *Hidden Harm*, Advisory Council on Misuse of Drugs, June 03, Home Office
- xxxiii *Alcohol Harm Reduction Strategy for England*, 2004
- xxxiv Various studies, Becker, Aldridge, Dearden et al for the Young Carers Research Group (YCRG) at Loughborough University
- xxxv *Young Carers in the UK The 2004 Report*, Dearden, C and Becker, S. Loughborough University Young Carers Research Group. 2004

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