Carers at the heart of 21st century families

Improving support for carers

The Government has produced a ten-year strategy – Carers at the heart of 21st century families and communities – to improve support for carers. It sets out a framework to ensure better health and social care support for carers and give them improved access to flexible working, education and leisure opportunities, and it aims to ensure children and young people are not providing unreasonable levels of care and have the support they need to learn, develop and thrive.

This Briefing summarises the strategy, its short-term commitments and longer term priorities, highlighting those that will have the most impact upon NHS organisations.

Key points

• The strategy focuses on services that support people and carers in their own homes.
• Over the next three years, pilots will look at how PCTs can better support carers.
• Over the next three years, everyone using social services, including carers, will receive a personal budget.
• PCTs will be required to produce joint plans with local authorities on how they will improve the quality and choice of carers’ breaks.
• The Government will produce a good practice guide for employers on the benefits of employing carers.
• Annual health checks for carers will be piloted in a number of PCT areas.
• Programmes and funding will be extended to help and support young carers.

Background

One in nine men and one in 11 women currently have caring responsibilities. Many people now need to balance work, childcare and caring for an aging parent. Increasing numbers of older people are caring for partners and also helping to look after their grandchildren. The number of people aged over 85 – the age group most likely to need care – is set to double over the next 20 years.

Previous initiatives

The Prime Minister launched the Caring about Carers strategy, including carers’ grants, in 1999. Carers were given the right to request flexible working in the Employment Act 2002 and Work and Families Act 2006. Carers benefited from the Carers and Disabled Children Act 2000 and Carers (Equal Opportunities) Act 2004, which gave them a range of new rights.

A ‘New Deal for Carers’ was announced in the 2006 white paper, Our health, our care, our say, which pledged:

• a national information helpline and website
The new strategy’s vision is that by 2018:

- carers will be respected as expert care partners and will have access to integrated and personalised services
- carers will be able to have a life of their own alongside their caring role
- carers will be supported so they are not forced into financial hardship by their caring role
- carers will be supported to stay mentally and physically well and treated with dignity
- children and young people will be protected from inappropriate caring and have the support to learn, develop and thrive.

**Integrated and personalised services**

In consultation, carers said they are often seen as being just a social care issue and that it can be difficult to engage the NHS in providing them with support. They called for more integrated working between the NHS, social services and carers.

To encourage better partnership working between health, social care and the third sector, over the next three years pilots will look at ways in which primary care trusts (PCTs) can better support carers. The pilots will gather evidence on how better service provision and interaction with carers in hospitals, GP surgeries and elsewhere is benefiting both carers and the NHS. They will look at:

- actively involving carers in diagnosis, care and discharge planning
- providing greater support for carers at GP practices and acute trusts
- working in partnership with local authorities and the third sector to provide flexible support for carers.

In the longer term, the Government will disseminate this best practice to PCTs. Other commitments include funding over the next three years to build capacity in the third sector, recognising the role it plays in supporting carers, and investment in training professionals in local authorities to support carers more effectively day-to-day and when making commissioning decisions.

**Personal budgets and direct payments**

In the longer term, the Government will consider extending flexibility in the way personal budgets and direct payments can be used. It would like more service users and carers to take advantage of the benefits that direct payments can bring and hopes new legislation will be enacted in 2009 to extend direct payments to those with mental incapacity. This would particularly benefit the carers of severely disabled children once they have reached the age of 18 and those of people with dementia and severe head injuries, giving them the flexibility to purchase services that are tailored to their particular needs.

Over the next three years, everyone using social services, including carers, will receive a personal budget as outlined in the 2007 document on
the transformation of adult social care, *Putting people first*. The new strategy hopes personal budgets can be used not only to purchase services for the person being cared for, but also to help carers in activities that they may find hard to do, for example by paying for someone to do the gardening.

Personal budgets will give carers and service users choice and control, but they will need improved advice and support in managing their budgets. Health and social care professionals often already support carers, but the Government is considering providing a lead professional for carers with significant needs to help them access services and ensure early intervention where necessary. It also wants to explore how all carers can access the specialist carers’ service irrespective of where they live.

### Ensuring carers have a life of their own

In the consultation, carers said breaks and high-quality replacement care were top priorities.

£150 million will be invested over two years on carers’ breaks. The money will be allocated to PCTs, who will be required to produce joint plans with local authorities on how they will improve quality and choice of break, taking into account both the new money and the existing money that is provided via carers’ grants. Options are expected to include holidays, sitting and befriending services and access to local leisure services. The Operating Framework for the NHS due to be published in Autumn 2008 will set out how PCTs can work with local authorities to deliver short breaks to carers in a personalised way.

Over the course of three years, pilots will be run in local authorities to encourage innovative approaches to the provision of breaks. The pilots will look at quality, cost-effectiveness and the use of personal budgets.

Local discount schemes for transport and leisure facilities are important to carers and there is a commitment in the strategy to help councils share good practice among themselves.

### Being a good employer

The strategy aims to reduce financial hardship and help carers, where appropriate, combine their caring duties with paid work. The role of the employer is crucial, not just in offering flexible working, but also in recognising that carers have specific needs. This could mean ensuring they have access to a telephone so that the person they care for can contact them if necessary, and understanding that carers may occasionally need to leave work early or suddenly. The Government will produce a good practice guide for employers on the benefits of employing carers.

More flexible opportunities for life-long learning for carers – for example, through more flexible hours and modular courses – will be encouraged.

### Key new commitments for the next three years

- PCT pilots will look at how the NHS can better support carers.
- Extra money will be provided to PCTs to provide breaks, including holidays and befriending services.
- Annual health checks for carers working the most intensely will be trialled in a number of PCT areas. Pilots will consider cost-effectiveness and benefits to carers and the NHS.
- A training programme for GPs will be developed to help them understand carers’ needs.
- Training materials for GPs and hospital discharge teams will be developed to help them understand the needs of young carers.
- A cross-government programme board will be set up to ensure implementation of commitments over the next two years and the necessary preparatory work to enable the development of longer term proposals.

### Maintaining health and well-being

1.25 million people provide over 50 hours of care each week and
these people are twice as likely as non-carers to be in poor health themselves. Annual health checks for carers will be piloted in a number of PCT areas. These are likely to focus on carers in the highest intensity roles. The pilots will explore cost-effectiveness and benefits to both the health service and the carer and, subject to positive evaluation, these health checks may be extended more widely. In the longer term, the Government will look into providing replacement care to allow carers to attend hospital appointments and health screenings.

Carers are more likely to suffer anxiety, depression and loss of confidence than non-carers, which can lead to self-neglect or the neglect or mistreatment of the person being cared for. Investment has already been committed to developing psychological therapy services across England. In addition, the Government will consider prioritising projects that provide emotional support to carers in the Department of Health review of grants to third sector organisations.

The Operating Framework for the NHS in 2008/09 says PCTs should aim to create a more personalised service that provides support for carers by recognising their need for breaks from caring. Providing breaks when these are necessary for the health and well-being of the carer is part of the work of the NHS.

Commissioning by PCTs and GP practices is key to helping carers, for example by purchasing respite care to give carers a break or arranging for intensive nursing care for set periods of time such as during terminal illness. Carer involvement is crucial to making correct commissioning decisions.

The role of GPs
GPs are often the first point of contact for carers and will normally be the professional in closest contact with them. There are currently three Quality and Outcome Framework points that incentivise GPs to provide support for carers. However, more needs to be done to ensure this is an outcome-driven rather than a process-driven measure. In the long term, the Government will discuss with GPs and other healthcare professionals what measures can be taken to give a sharper focus to the distinct needs of carers.

The Department of Health will work with the Royal College of General Practitioners to develop, pilot and evaluate a training programme for GPs to help them better understand carers’ needs. Modules will be tailored to the needs of specific groups of carers, such as those from black and minority ethnic groups, and content will be developed with help from carers, whom the Government also hopes will be actively involved in the delivery of training. The training programme may be rolled out nationally and might also influence the initial training that doctors receive before qualifying as GPs.

Information prescriptions
Information prescriptions will play a key role in enabling carers to become expert care partners. They will be issued by health and social care professionals and guide carers on where they can find relevant and reliable sources of information specific to their needs, which will help them and the people they care for make better informed choices.

‘Tailored training materials for GPs and hospital discharge teams will be developed to help them take better account of the needs of young carers’

The Government will introduce the legislation needed for carers to receive appropriate healthcare information about the person they are caring for, especially in cases where mental incapacity is an issue.

Supporting young carers
There are 139,000 children and young people under the age of 18 in England providing some care to family, friends or neighbours. Caring can be a positive experience, helping to foster maturity and independence and strengthen family ties. However, it can also affect school attendance, educational achievement and emotional and physical well-being. Young carers are also at greater risk of social isolation and bullying.

In consultation, young people said they did not want to stop caring altogether but also wanted time to study and be with friends.

Young carers need clear and timely information from healthcare professionals to support them in their role. Tailored training materials for GPs and hospital discharge teams will be developed to help them take better account of young carers’ needs as both children and carers.

A number of initiatives exist to support young carers, including the Extended Family Pathway programme which supports families who may be...
at risk of relying on the care of a child. This programme will be extended to a further 12 or 13 local areas. Learning from the programme will be shared across all local areas over the next three years.

The Government is also making £1 million available to support new and innovative work by projects that help prevent young people from undertaking excessive caring. Projects will bid for funding and will be expected to work closely with councils and PCT-funded services which are already supporting the family. Further funding will be given to an expanded programme of local and regional training on whole-family working for staff in local services. This will target teams working in adult mental health and substance misuse services in particular.

Further research will be commissioned to look at the patterns of support needed by families affected by disability, illness and substance misuse. It will look at whether further service change might be needed beyond 2011 to protect children from inappropriate caring.

Ensuring implementation

Robust arrangements will be put in place to ensure progress in implementation over the next ten years.

A new cross-government programme board will ensure the commitments made for the next two years are implemented and that the necessary preparatory work is undertaken to support the delivery of the longer term proposals. The board will include senior representatives from government and key delivery partners. It will complement the Standing Commission on Carers, set up in December 2007 to advise the Government on progress in implementing the strategy. The Standing Commission will also advise the Government on ways in which carers can be supported further in light of changing expectations of society.

Improving data

Further data on carers needs to be gathered. A carer experience survey will be developed, with the Information Centre, for local authorities to undertake on a voluntary basis in 2009/10 to help inform the commissioning of carers’ services. The survey will ask carers whether they are receiving the services they need and what they think of the quality of those services. A question on carers will be included in the 2011 Census to enable comparisons with the 2001 Census. In addition, a module on carers will be included in an Omnibus Survey in 2008/9. The module will contain a number of questions about carers, including health and social services, employment, income and housing. In the longer term, the Government will review the National Indicator Set to ensure carers’ experiences of services are measured.

NHS Confederation viewpoint

Many of the people for whom NHS organisations provide services receive most of their care from unpaid and informal carers, both from within the family and from their immediate neighbourhood. This support is widely acknowledged to be invaluable, particularly for those with long-term conditions, and in a lot of cases is the difference between individuals being looked after in their own home and the need for residential care being considered.

The NHS Confederation, therefore, welcomes this strategy which builds on existing guidance and broadens it to improve carers’ access to information, support and training. As a major employer, we are pleased to see the links being made between employment and carers’ issues, particularly with the publication of the good practice guide for employers and the investment in extending emergency care cover.

With 1.25 million carers providing over 50 hours of care per week, it is vital that carers do get better access to services which promote their own well-being. Whilst annual health checks could be one answer, the Confederation supports the fact that such approaches will need to be piloted to ensure that they meet the needs of individual carers and their circumstances in different parts of the country. The implementation of local discount schemes for transport and leisure will also require joint working at local strategic partnership level and this commitment to joint commissioning, involving carers in developing services, is to be welcomed.

We also look forward to the next phase of work, outlined in the strategy, on the potential reform of the benefits system to support carers.
in their role, which will be vital in the development of a system in which carers are acknowledged as true partners in the delivery of care.

Lastly, the Confederation notes the thrust towards personal budgets outlined in the strategy. We will continue to work on this area of policy, particularly in how it can be developed across health and social care. There is a balance to be struck in the funding of packages of care for people with long-term conditions and the implications for carers of personal budgets in health, as outlined in the NHS Next Stage Review, will need to be taken into consideration. We look forward to continuing this debate.

For more information on the issues covered in this Briefing, contact jo.webber@nhsconfed.org

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**Further information**

*Putting people first: a shared vision and commitment to the transformation of adult social care.*

*Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own.*

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**The NHS Confederation**

The NHS Confederation is the independent membership body for the full range of organisations that make up today’s NHS across the UK. Our members include primary care trusts, NHS trusts, NHS foundation trusts and independent providers of NHS services. Our ambition is excellence for patients, the public and staff by supporting leadership of the new NHS. Together, we help our members improve health and health services by:

- influencing policy, implementation and the public debate
- supporting leaders through networking, sharing information and learning
- promoting excellence in employment.