

# Supporting Carers:

An action guide for general practitioners and their teams

SECOND EDITION



The Princess Royal Trust  
for Carers



Royal College of  
General Practitioners





Introduction from  
**Liz Fenton**  
Chief Executive, 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 productive relationship for both organisations.

It is estimated that 6,000 people take on caring responsibilities every day, looking after a family member or friend with a disability or long term condition, mental health problem, or alcohol or substance misuse issue.

Our health and social care systems depend on the caring role they undertake. However, 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.

However, many carers go unidentified until many years into their caring role. Reaching carers early is vital – not just so that they can play a full role in the care of their family member or friend, but also so that their own health and wellbeing needs can be addressed. GP practices can take a number of easy steps to embed the identification and support of carers within their practice, working with their local carers' organisations, which will mean more carers are supported earlier – with real benefits for carers, patients, and practices alike.

This guide shows some of the excellent work already carried out by GPs, their practice teams and local Carers' Centres and other organisations, and gives an action guide on how to address some of the issues which arise. 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.



Introduction from  
**Dr Clare Gerada**  
**Chair, Royal College of General Practitioners**

Carers often neglect their own healthcare needs and in many cases it is only a matter of time before they become ill. Most people visit their GP surgery, either for their own health or while looking after the person they care for, so we can play a crucial role in identifying patients with caring responsibilities at an early stage. We can also encourage them to look after their own health and ensure that they receive the right support to stay healthy, maintain a life of their own and continue caring.

GPs are working very hard to develop and improve their services for carers and this excellent resource will ensure that primary care teams across the country are better equipped to provide a wide range of support.

We are delighted to be working in partnership with The Princess Royal Trust for Carers on this and other initiatives to equip GPs with the knowledge and support they need to deliver the best care possible to those who are carrying out such an important – but often unnoticed and undervalued – role.



Introduction from  
**Professor Nigel Sparrow**

**Chair, Professional Development Board, Royal College of General Practitioners**

The contribution of carers is vital to the delivery of both health and social care and to the wider economy, and GPs and their teams are in an ideal position to help and support carers. About 6000 people take on the role of caring every day. We know that carers' health suffers as a result of caring so it is really important that we are able to identify carers so that we can provide much needed help and support.

Personal continuing relationship-based care is fundamental to our role as GPs. The relationship between carer and GP practice is a special one and should be recognised as a partnership in care. The guide 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.

# Contents

## SECTION ONE

1.1 Who are carers?	7
1.2 What do carers do?	10
1.3 Effects of caring on carers	11
1.4 Carers as partners in care	13
1.5 Life after caring	14
1.6 Policy context	15

## SECTION TWO

2.1 Carers' leads	20
2.2 Finding and recognising carers	20
2.3 Involving carers in patient care	23
2.4 Improving healthcare for carers	25
2.5 Information and support for carers	28
2.6 Supporting young carers	30
2.7 Auditing carer support	32

## APPENDICES

1 Developing your Practice Action Plan	34
2 Self-Assessment Checklist	35

*A carer is a person of any age, adult or child, who provides unpaid support to a partner, child, relative or friend who couldn't manage to live independently or whose health or wellbeing would deteriorate without this help. This could be due to frailty, disability or serious health condition, mental ill health or substance misuse.*

## Why should you read this guide?

Just over one in ten patients on any GP practice list is a carer, although many go unrecognised. Carers provide extremely valuable support to the people that they look after. They enable people to maintain their independence and quality of life. As a society, we do not have the financial resources to provide this level of individual support without them.

### However caring comes at a cost:

- Up to 40% of carers experience psychological distress or depression<sup>1</sup>
- Carers have an increased rate of physical health problems<sup>1</sup>
- One in five gives up work to care<sup>2</sup>, and
- More than half fall into debt as a result of caring<sup>3</sup>.

Carers look to GPs and other members of the Primary Care Team for support both for themselves, and also for the people that they care for. Carers' knowledge about the person being cared for and co-operation are vital for planning and implementing any care plan successfully. Therefore, engaging and co-operating with carers is an essential part of good patient care.

This guide will help you to understand who carers are, why they need your help, how you can involve them in patient care, and how your practice can give them the support that they need and deserve. It will also demonstrate why providing that support is to the advantage of your practice team.

### Five key ways for GPs and primary care teams to support carers<sup>4</sup>

1. Just listen!
2. Think of depression
3. Ask about finances
4. Signpost to services
5. Plan for emergencies

<sup>1</sup> Pinquart M, Sorensen S. Differences between caregivers and non-caregivers in psychological health and physical health: a meta-analysis. *Psychology and Aging* (2003) 18 (2), pp. 250-267

<sup>2</sup> Carers UK. Real change not short change: Time to deliver for carers (2007) Accessed via: [www.carersuk.org/Professionals/ResearchLibrary/Financialimpactofcaring/1201109152](http://www.carersuk.org/Professionals/ResearchLibrary/Financialimpactofcaring/1201109152)

<sup>3</sup> Carers UK. Carers in Crisis (2008) Accessed via: [www.carersuk.org/Professionals/ResearchLibrary/Financialimpactofcaring](http://www.carersuk.org/Professionals/ResearchLibrary/Financialimpactofcaring)

<sup>4</sup> RCGP/e-Learning for Health Supporting Carers in General Practice (2011). Accessed via: [www.e-lfh.org.uk/projects/supportingcarersingeneralpractice/index.html](http://www.e-lfh.org.uk/projects/supportingcarersingeneralpractice/index.html)

# Carers: the facts

1.1 Who are carers?	7
1.2 What do carers do?	10
1.3 Effects of caring on carers	11
1.4 Carers as partners in care	13
1.5 Life after caring	14
1.6 Policy context	15

## 1.1 Who are carers?

*A carer is a person of any age, adult or child, who provides unpaid support to a partner, child, relative or friend who couldn't manage to live independently or whose health or wellbeing would deteriorate without this help. This could be due to frailty, disability or serious health condition, mental ill health or substance misuse.*

There are approximately 6 million carers in the UK. Although there are slightly more women than men who are carers, and carers are most commonly aged 45-64, carers can be of all ages and from all parts of society. Carers are not always fit and healthy themselves and may have their own health needs. They may look after more than one person, for example a child with a disability and an elderly relative.

- 1.25 million carers in the UK do caring tasks for more than 50 hours per week
- An additional two million carers care for more than 20 hours per week
- 2.9 million carers combine paid employment with caring for somebody else<sup>5</sup>
- 49% of current carers have been providing care for more than five years<sup>6</sup>

Although carers do not generally choose to be carers, most prefer to look after their family members or friends themselves than have someone else care for them. It is a role that may come suddenly and unexpectedly, for example after injury or sudden illness. Alternatively the carer's role may creep up over time if the person has a progressive illness. Approximately, two million people move in and out of caring roles every year<sup>7</sup>.

It is important to recognise that some carers do not regard themselves as a carer, or may dislike the label "carer", believing that it can detract from their identity as a parent, child, partner or sibling to the person that they care for. It is also important not to confuse carers with paid care workers.

### The diversity of carers

The following are carer stories that reflect the diversity of carers that you might see in your practice:

Mohammed is 22 and lives with his mum who has schizophrenia. She is currently going through a bad patch.

Ethel is 84 and is looking after her husband who has dementia.

Julie is 36 and a single, working mum. Her father has cancer. He is a widower and so Julie is trying to juggle work, looking after her daughter and providing practical and emotional support to her father who lives over 100 miles away.

Amy is 14. Her mother has multiple sclerosis. Her father has given up work to look after her mother, but relies on Amy to give him a break and help out when she comes home from school.

Pavel is 62. He has rheumatoid arthritis. His wife has just been discharged home from hospital following a stroke.

*Reproduced with permission from Simon C. Carers: facts and figures. InnovAiT 2011: 4(8) p. 432 - 437*

### Young adult carers

There are in excess of a quarter of a million carers aged 18-24 in the UK with 12% caring for more than 50 hours a week. It may be difficult for young adult carers to leave home because of emotional pressures, demands for care in the home, or the burden that leaving might place on younger siblings. Competing demands on their time through pressures to succeed at work, do well in

education, or maintain new personal relationships can make caring particularly difficult for this age group<sup>8</sup>.

## Young carers

Young carers are under the age of eighteen and carry out significant caring tasks. This situation can arise when families who have a child, parent or grandparent needing care are not offered appropriate help and support from health or social care services. Children then have to take on inappropriate levels of caring responsibilities.

The 2001 census identified 175,000 young carers<sup>9</sup>. However this is likely to be a significant underestimate. A recent BBC poll of secondary school children found that 8% of secondary school children had moderate or high levels of care responsibilities. This translates to a figure of approximately 700,000 young carers across the UK<sup>10</sup>. The true figure may be even higher and nearer a million, as this figure only relates to children of secondary school age. Data collected in 2003 from projects supporting young carers suggested that 71% of young carers were between the ages of 11 and 18; the remainder were aged 5-10 years<sup>11</sup>.

## 1.2 What do carers do?

The tasks that carers perform depend on a number of factors, including:

- Factors relating to the person being cared for. For example, a person with mental health problems will have very different care needs to a person with paralysis.
- Factors relating to the carer. For example, if the carer works or has other caring responsibilities he or she might not have the time to perform some caring tasks. Similarly, if the carer has previous expert nursing experience he or she might take on tasks that other carers would find too demanding.

- Factors relating to the environment. For example, which services are available locally or whether the carer lives in the same home as the patient.

Caring tasks are many and varied. Commonly carers might perform domestic tasks such as shopping, managing finances, cleaning, gardening, washing and ironing; maybe in addition to maintaining their own separate households. Carers often do nursing tasks such as giving medication, changing dressings and helping with mobility. They may provide intimate care including washing the person cared for, dressing and attending to toileting needs. This may include a great deal of lifting, or changing soiled clothes many times throughout the day. They may need to supervise medication or help with communication.

Other carers, such as those caring for people with mental health or substance misuse problems, or those caring for people with dementia, may perform few physical tasks, but provide a great deal of emotional support, including help to ensure that the person that they care for stays safe. Carers may provide child care when parents are not able to care for their children themselves.

Anne cares for her 16-year-old-daughter, Paula, who has "Deletion syndrome". Paula experiences mental health issues and physical disabilities. Paula needs help with all aspects of her daily living as she is unable to do these herself and Anne has to tube feed her four times a day. Paula also has epilepsy and some of her seizures affect her breathing meaning that Anne sometimes has to do emergency cardiopulmonary resuscitation to prevent her from asphyxiating. As a result of lifting Paula from room to room and in and out of her wheelchair, Anne now suffers from a bad back.

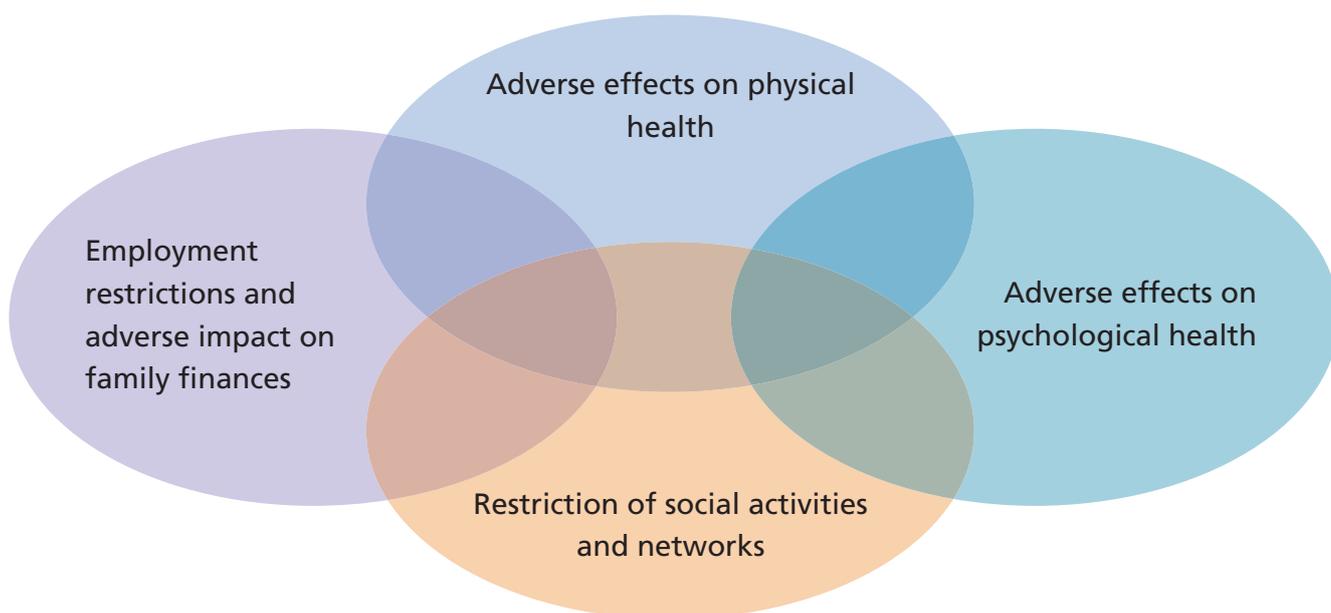
*Further information: [www.carers.org/annes-story](http://www.carers.org/annes-story)*

They may also need to deal with emergencies; frequently at times that are far from convenient.

The 1.25 million carers who provide care for more than 50 hours each week equate to a full-time workforce larger than the entire National Health Service (NHS). Carers are estimated to save the UK economy £119 billion a year in care costs. This is equivalent to £18,473 per year for every carer in the UK<sup>12</sup>. At the time that this calculation was made, this figure exceeded total Government spending on the NHS, and was several times the spending on social services. Our society could not afford to provide the current level of community care without this willing army of unpaid support. Carers are therefore vital to both our society and our economy.

### 1.3 Effects of caring on carers

Although many carers gain great personal satisfaction from their caring role and want to continue caring, there is evidence to suggest that they often experience negative health, social and financial consequences as a result. These effects impact upon each other.



### Health effects of caring

The Government has highlighted carers as a group experiencing comparative poor health within their plans to promote public health<sup>13</sup>. Research on populations of carers has consistently demonstrated that caring has a pronounced adverse effect on psychological health:

- 40% of carers have significant distress and depression levels<sup>14</sup>.
- Carers providing more than 20 hours of care per week over extended periods have twice the risk of experiencing psychological distress over a two year period than non-carers; the risk of distress increases progressively with the amount of time devoted to caring each week and adverse effects of caring are evident beyond the end of caring episodes<sup>15</sup>.

Effects of caring on physical health are less clear. In one survey, 20% reported back injury as a result of caring (mainly carers doing heavy physical caring for those with physical disabilities) and 10% put their high blood pressure down to the stress of caring<sup>16</sup>. Although survey findings can be criticised because the populations surveyed are not necessarily representative of all carers, and the health problems are self-reported, research studies using more diverse populations of carers support a

negative effect of caring on physical health. In particular:

- Older carers who report 'strain' have a 63% higher likelihood of death in a 4 year period than non-carers or carers not reporting strain<sup>17</sup>.
- Providing high levels of care is associated with a 23% higher risk of stroke<sup>18</sup>.

## Social and economic effects of caring

Caring can impact on all dimensions of family functioning and wellbeing. Many carers emphasise positive reasons for caring despite dramatic changes in family dynamics. However, carers also report adverse effects of caring on their social functioning, including restricting their activities, deterioration of relationships with other family members and social isolation. Carers find that the social support that they have reduces both in quantity and quality over time, and they generally have smaller social networks than other people. Perceptions of the availability of social support are associated with positive mental health outcomes for carers<sup>19</sup>.

Caring can affect paid employment and job prospects:

- 20% of carers give up work to care
- On average, carers retire 8 years early.
- In 87% of households with working-age carers looking after their partners, no-one in the household is in paid employment<sup>20</sup>.
- Effects of caring can also be more subtle, for example by hindering promotion prospects.

By the time the additional costs of looking after a person with a disability and the negative impact of caring on work are taken into consideration, the majority of carers find that they are worse off as a result of caring. For many carers, their financial situation is so difficult that they are struggling to pay even basic bills. Financial problems are directly related to the amount of care provided i.e. the more care provided, the more likely a carer is to be in financial difficulty. In one Carers UK survey:

- 52% had cut back on buying food.

- 65% of carers were in fuel poverty.
- 74% had difficulty paying essential utility bills.
- Over half (55%) were in debt as a result of their caring responsibilities<sup>21</sup>.

Despite the adverse financial effects of being a carer, many carers do not claim all the benefits that they are eligible for, such as Carers' Allowance. One survey found that 81% of respondents had been caring for over a year before they received financial support, and just under half of these had been caring for 5 years before getting support<sup>22</sup>. Half felt that they had missed out on benefits.

## Adverse effects of caring on young carers

Much less is known about the health effects of caring on young carers than on adults. However, they may report:

- Feeling worried, anxious or stressed about caring responsibilities and the person they care for.
- Physical injuries (e.g. back strain or muscular injuries) as a result of caring duties.
- Missing healthcare appointments with doctors or dentists.
- Poor diet because of financial constraints on the family food budget, or because they have responsibility for preparing meals but lack basic cooking skills.
- Behaviour problems, particularly self-harm<sup>23</sup>.

There may be conflict between the needs of the young carer and those of the person being cared for. This may lead to feelings of guilt, anger, isolation (no-one else understands their experiences), or being trapped. Young carers are also more likely to suffer traumatic life events such as death of a parent or sibling.

Young carers may have difficulties playing or socialising with other children, and joining in with sporting and leisure activities as a result of lack of time due to caring responsibilities and/or lack of

parental support. For this reason, young carers often have restricted peer networks. They may also find that they are mature beyond their years and have little in common with same-age peers. These factors may contribute to the relatively high levels of bullying that young carers report<sup>24</sup>. Many continue to have emotional problems into adulthood and may have ongoing difficulties establishing relationships<sup>25</sup>.

For just over one in five young carers (22%), caring has a negative impact on education. Educational difficulties are more common in the 11-15 year old age group<sup>25</sup> and include:

- Increased absences and/or lateness.
- Failure to submit homework or coursework, or poor quality work.
- Tiredness, poor concentration and/or lack of attention.
- Under-attainment which may restrict higher education options, and job prospects long-term.

## 1.4 Carers as partners in care

*“NHS services must reflect the needs and preferences of patients and 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 NHS Constitution for England (2009)<sup>26</sup>.

Carers know the people that they care for better than anyone else. This knowledge can be extremely useful in planning patient care, and also in identification of problems that may require intervention. If care is planned without the input of carers, an opportunity has been lost. Therefore, engagement and co-operation with carers is an essential part of good patient care.

Furthermore, co-operation is needed from carers to effectively implement any patient care plan. Involving carers when devising a care plan and

listening to their views is likely to result in better co-operation and concordance.

### Reducing unwanted admissions

Admission into hospital or residential care can be an indication of a breakdown in the caring relationship because a carer is no longer able to care, often because the strain of caring has caused physical or mental ill health. One study found that problems associated with the carer contributed to hospital readmission in 62% of cases<sup>27</sup>. Carers of people admitted to hospital were more likely than other carers to:

- Be experiencing ill health, fatigue and interrupted sleep.
- Be conducting at least one intimate task.
- Generally feel frustrated.

Another study tracked people aged over 75 years and found that 20% of those needing care were admitted to hospital because of the breakdown of a single carer on whom the person was mainly dependent<sup>28</sup>. Other studies have shown that providing carers with breaks, emotional support and access to training can significantly delay the need for the person receiving care to go into residential care.<sup>29</sup>

### Improving patient and carer well-being

Other research into the benefits of involving carers as partners in care has focused on improving patient and carer well-being. Evaluations of four re-ablement programmes in England have found that involving and supporting carers can improve re-ablement of patients<sup>30</sup>.

In the area of stroke care, one randomised controlled trial (RCT) found that support for the family of patients who have suffered a stroke is linked with reduced depression in those patients (17% - 27%) and a reduced need for physiotherapy<sup>31</sup>. Another RCT found that personal care training for carers resulted in a higher proportion of patients who have had a stroke

achieving independence at an earlier stage, and reduced the need for physiotherapy and occupational therapy. There were also significant reductions in carer burden and improvements in mood and quality of life for carers and care recipients<sup>32</sup>.

## 1.5 Life after caring

*“For so long, it’s like I’ve been living in a dark tunnel that gets narrower, but now I’ve reached the light at the end, I feel completely blinded by it.”*

The National Strategy for Carers encourages carers to maintain a life of their own but in reality their identity is likely to have been shaped by their role as a carer. As a result, when their caring responsibilities come to an end, they question what else they are able to do. Time lost from education, employment, personal and family relationships will have inevitably affected the life choices of former carers. Ongoing support is needed throughout this period of time.

Problems commonly seen when carers stop caring include:

- Feelings of emptiness and void.
- Low self-esteem, depression, anxiety, and/or self-destructive behaviour such as alcohol abuse.
- Without the company of the cared for person, loneliness and more social isolation than before.
- Poor health as a result of years of self neglect, back strain, lack of sleep and stress.

Every caring experience is different. How a person copes with life after caring depends very much on the length and complexity of the caring responsibility and the relationship between the carer and the cared for person. It also depends on how it ends:

**Death** of the care recipient may result in a sense of shock, even if the person has been ill for a long time. Benefits often come to an end within a few weeks of death and there may be housing issues if the person who has died owned or was leaseholder for a joint home.

**Admission into residential care** also results in a sense of bereavement. Often, such a move is the only feasible option but the carer may still suffer from feelings of guilt and anxiety. Although the carer will continue to be a carer, albeit from a distance, he or she may feel a sense of failure. In addition, there may be financial implications and, after many years of rarely being able to leave home, the carer will lack confidence in seeking a life away from their caring responsibilities or outside employment.

**Varying care needs** may result in carers moving in and out of a caring role. For example, where a family member misuses alcohol or drugs or has mental health issues or an eating disorder, a carer’s responsibilities will vary according to the current state of health of the person with care needs. However, even when that person appears to be coping well, the carer will always have the stress of wondering what the future will bring and uncertainty of not knowing when their help will be needed urgently.

### Young carers

If a child or young person is required to take on a caring role, this responsibility so early in life can affect relationships with others and as a result, former young carers may have their entire lifetime affected by their early caring role. It can create a heightened sense of responsibility for the health and welfare of others and act as a barrier to balanced relationships. Young carers need help to regain confidence in their own identity and the ability to go forward independently of their caring role.

## 1.6 Policy context

The Government has recognised the importance of carers and has taken a number of steps to ensure that they are supported through health services and local authorities. These depend on good local implementation if carers are to be supported effectively.

### The Quality and Outcomes Framework (QOF) and carers

The QOF includes an indicator (Management 9) which relates to identification of carers: 'The practice has a protocol for the identification of carers and a mechanism for the referral of carers for social services assessment'<sup>33</sup>. This is worth three QOF points to the practice.

However, although 98% of practices in England and Wales received these points in 2009/10<sup>34</sup>, less than 1% of practice lists are identified as carers compared to approximately 10% of the population being carers<sup>35</sup>. This means large numbers of carers are not being recognised by their GP practices, yet general practice is a key gateway to support for them.

#### Find out how many carers are registered with your practice

*How many patients do you have on your practice list?*

*How many carers would you expect to have on your practice list? (Divide your practice list size by 10 to give an estimate)*

Amongst every 100 patients on your practice list, you would expect:



### Government focus on improving carer support

The Government published 'Recognised, valued and supported: Next steps for the Carers' Strategy' in November 2010. This document focuses on improving health and social care support for carers in England. Four areas have been prioritised, the first three of which GP practices can clearly influence:

- Supporting early self-identification and involvement in local care planning and individual care planning.
- Personalised support for carers and those receiving care.
- Supporting carers to remain healthy.
- Enabling carers to fulfil their educational and employment potential.

### Health and social care

Following an assessment, a disabled person's and carer's needs are categorised as being critical, substantial, moderate or low and a decision is made by the local authority on how much social care support they will be offered. In many areas, support is not provided by the local authority unless the needs are assessed as being at the higher end of this spectrum.

The Government is encouraging greater coordination between health and social care, and believes that councils and the NHS should be pooling budgets and jointly commissioning services. It is also committed to maintaining the drive towards personalisation of public services in health, social care and beyond. Personalisation aims to ensure that services are accessible to all, and that *everyone* in the community has more choice and control through provision of information, advice and advocacy.

Increasingly social care support for disabled people and carers is being provided by local authorities through a personal budget. People eligible for social care support are told how

much money is allocated for their support so that they can have more choice in how this money is spent on their needs. A personal budget should wherever possible be given as a direct payment to the individual to administer, but it is important that good support is available so that managing the budget does not become an unwanted extra burden. Alternatively a personal budget can be held and managed by the local authority or placed as an account with a third party provider (such as a trust or local charity), but the individual maintains control of how the money is spent. Personal budgets for health services are currently being trialled, based on their use in social care.

### **Government funding available to support carers**

Between 2011 and 2015, as part of its Carers' Strategy, an additional £400 million has been provided in allocations made to Primary Care Trusts in England (and commissioning consortia subsequently) to improve support for carers of all ages. Councils also receive a Carers' Grant within their General Local Government Allowance Grant, rising in line with inflation from 2011-15. Some authorities are using this money to work with GP practices to reach and support carers. This funding is not, however, ring-fenced and so local NHS trusts can set their own priorities for how these are spent.

### **Discharge from hospital**

Local Authorities and the NHS share responsibility for patients at the point of discharge from hospital, with Government advising that carers should be involved in discharge planning and that carers can ask for an assessment of any services that they need to support the discharge of the person that they care for. However, two thirds of carers have not been asked whether they can cope after the discharge of the person that they care for, and only a quarter feel that the hospital has helped them to prepare for discharge<sup>36</sup>.

## **Prescribing breaks for carers in Cambridgeshire**

In 24 practices in Cambridgeshire, GPs can issue carers with a free prescription to contact Crossroads Care Cambridgeshire ([www.crossroadscarecambridgeshire.org.uk](http://www.crossroadscarecambridgeshire.org.uk)) who will visit the carer and help them access the support they need and want. If the carer wants a break, it can be booked directly through Crossroads Care and at no charge to the carer. There are also free support group sessions that carers can join. The cost of the prescriptions is underwritten by the Primary Care Trust (NHS Cambridgeshire) and is available for carers of any age. GP commissioning groups have supported expansion of the service to all 77 practices in Cambridgeshire. As one GP said, "Previously, we were required to compile a carers' register. But what do you do with it? Now we've now got a real resource we can attach to it."

*Further information: email*

*[care@crossroadscarecambridgeshire.org.uk](mailto:care@crossroadscarecambridgeshire.org.uk) or call*

*0845 241 0954*

### **Responsibility to young carers**

It is important to provide support to all carers in order to protect them from negative consequences of caring and maintain the family situation. However, in children this is particularly important. The GP and primary care team have a responsibility to young carers to ensure they are well supported, enabled to grow and develop normally and are not required to take on inappropriate caring roles:

■ Paragraph 3.62 of the Department of Health Framework for the Assessment of Children in Need and their Families (2000) states that '*young carers should not be expected to carry inappropriate levels of caring which have an adverse impact on their development and life chances*'<sup>37</sup>.

- The United Nations (UN) 'Convention on the Rights of a Child' states that every child has the right to participate fully in family, cultural and social life<sup>38</sup>; it is an integral part of the primary care team's role in safeguarding children to uphold this convention.
- The General Medical Council (GMC) pamphlet '0-18 years: Guidance for all doctors' (2007) stipulates that doctors should be aware of the needs and welfare of children and young people when they see patients who are parents or carers, or who are cared for by children or young people<sup>39</sup>.

- <sup>5</sup> These three statistics are taken from Census 2001
- <sup>6</sup> NHS Information Centre for Health and Social Care (2010), 'Survey of Carers in Households 2009-10'. London: Health and Social Care Information Centre
- <sup>7</sup> Carers UK (2008), 'In the Know; the importance of information for carers'
- <sup>8</sup> Becker F, Becker S. *Young adult carers in the UK: Experiences, needs and services for carers aged 16-24* (2008). The Princess Royal Trust for Carers. Accessed via: <http://static.carers.org/files/yac20report-final-241008-3787.pdf>
- <sup>9</sup> Doran T, Drever F, Whitehead M. Health of young and elderly informal carers: analysis of UK census data. *British Medical Journal* (2003) 327, p. 1388. Accessed via: [www.bmj.com/content/327/7428/1388.full.pdf](http://www.bmj.com/content/327/7428/1388.full.pdf)
- <sup>10</sup> BBC Press release. "Hidden Army" of young carers could be four times as high as official figures (16.11.2010). Accessed via: [www.bbc.co.uk/pressoffice/pressreleases/stories/2010/11\\_november/16/carers.shtml](http://www.bbc.co.uk/pressoffice/pressreleases/stories/2010/11_november/16/carers.shtml)
- <sup>11</sup> Dearden C, Becker S. *Young carers in the UK – the 2004 report*. Carers UK and The Children's Society. Accessed via: [www.carersuk.org/Professionals/ResearchLibrary/Profileofcaring/1207234991](http://www.carersuk.org/Professionals/ResearchLibrary/Profileofcaring/1207234991)
- <sup>12</sup> University of Leeds/Carers UK. *Valuing carers 2011: Calculating the value of carers' support* (2011). Accessed via: [www.carersuk.org/professionals/resources/research-library/item/2123-valuing-carers-2011](http://www.carersuk.org/professionals/resources/research-library/item/2123-valuing-carers-2011)
- <sup>13</sup> HM Government. *Healthy lives, health people: a strategy for public health in England* (2010) London: The Stationery Office
- <sup>14</sup> Pinquart M, Sorensen S. Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychology and Aging* (2003) 18 (2), pp. 250-267
- <sup>15</sup> Hirst M. Carer distress: A prospective, population-based study. *Social Science & Medicine* (2005) 61, 697-708.
- <sup>16</sup> Princess Royal Trust for Carers. *Carers Health Survey* (2004) Accessed via: <http://static.carers.org/files/carershealthsurvey-12.pdf>
- <sup>17</sup> Schulz R & Beach S. Caregiving as a risk factor for mortality. *Journal of the American Medical Association* (1999) 282 (23); pp. 2215-2219
- <sup>18</sup> Haley WE, Roth DL, Howard G, Safford MM. Caregiving strain and estimated risk for stroke and coronary heart disease among spouse caregivers. *Stroke* (2010) pp. 331-336
- <sup>19</sup> Simon C, Kendrick T, Kumar S. Cohort study of informal carers of first-time stroke survivors: a profile of health and social changes in the first year of care giving. *Social Science & Medicine* (2009) 69:3, pp. 404-410
- <sup>20</sup> Carers UK. *Real change not short change: Time to deliver for carers* (2007) Accessed via: [www.carersuk.org/Professionals/ResearchLibrary/FinancialImpactofcaring/1201109152](http://www.carersuk.org/Professionals/ResearchLibrary/FinancialImpactofcaring/1201109152)
- <sup>21</sup> Carers UK. *Carers in Crisis* (2008) Accessed via: [www.carersuk.org/Professionals/ResearchLibrary/FinancialImpactofcaring](http://www.carersuk.org/Professionals/ResearchLibrary/FinancialImpactofcaring)
- <sup>22</sup> Carers UK. *In the know* (2006) Accessed via: [www.carersuk.org/Professionals/ResearchLibrary/Profileofcaring/1201108799](http://www.carersuk.org/Professionals/ResearchLibrary/Profileofcaring/1201108799)
- <sup>23</sup> Poustie A, Neville R. Deliberate self harm cases: a primary care perspective. *Nursing Standard* (2004) 18 (48): 33-36
- <sup>24</sup> Dearden C, Becker S. *Young carers and education* (2003). Carers UK. Accessed via: [www.ukraids.org/departments/ss/centres/YCRG/youngCarersDownload/yceduc%5B1%5D.pdf](http://www.ukraids.org/departments/ss/centres/YCRG/youngCarersDownload/yceduc%5B1%5D.pdf)
- <sup>25</sup> Becker F, Becker S. *Young adult carers in the UK: Experiences, needs and services for carers aged 16-24* (2008). The Princess Royal Trust for Carers. Accessed via: <http://static.carers.org/files/yac20report-final-241008-3787.pdf>
- <sup>26</sup> Department of Health. The NHS Constitution (2009). Accessed via: [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_113613](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113613)
- <sup>27</sup> Williams, E., Fitton, F. (1991) Survey of carers of elderly patients discharged from hospital. *British Journal of General Practice*, 41, 105-108.
- <sup>28</sup> West Byfleet (1998), Pilot Study in West Byfleet, Surrey: Developing a whole system approach to the analysis and improvement of health and social care for older people
- <sup>29</sup> Mittelman MS, Ferris SH, Shulman E, Steinberg G, Levin B. Journal of the American Medical Association. (1996) 'A Family Intervention to Delay Nursing Home Placement of Patients With Alzheimer Disease: A Randomized Controlled Trial' Dec 4;276(21):1725-31.
- <sup>30</sup> Pg 31, Homecare Re-ablement Workstream, Care Services Efficiency Delivery Programme, 2007. Department of Health.
- <sup>31</sup> Mant J, Carter C, Wade D, Winner S. Family support for stroke: a randomised controlled trial. *Lancet* (2000): 356 pp. 808-813.
- <sup>32</sup> Kalra L, Evans A, Perez I, Melbourn A, Patel A, Knapp M, Donaldson, N. Training carers of stroke patients: Randomised controlled trial. *BMJ* (2004): 328 pp. 1099-1101
- <sup>33</sup> BMA/NHS Employers. *Quality and Outcomes Guidance for GMS Contract 2011/12* (2011). Accessed via: [www.nhsemployers.org/SiteCollectionDocuments/QOFGuidanceGMScontract\\_2011\\_12\\_FL%2013042011.pdf](http://www.nhsemployers.org/SiteCollectionDocuments/QOFGuidanceGMScontract_2011_12_FL%2013042011.pdf)
- <sup>34</sup> NHS Information centre for Health and Social Care. *England level QOF tables: 2009-10 – Organisational* (2010). Accessed via: [www.ic.nhs.uk/statistics-and-data-collections/supporting-information/audits-and-performance/the-quality-and-outcomes-framework/qof-2009-10/data-tables/england-level-data-tables](http://www.ic.nhs.uk/statistics-and-data-collections/supporting-information/audits-and-performance/the-quality-and-outcomes-framework/qof-2009-10/data-tables/england-level-data-tables)
- <sup>35</sup> 2001 Census and 2009/10 Household Survey.
- <sup>36</sup> ADASS. Carers as partners in hospital discharge(2010). Accessed via: [www.adass.org.uk/images/stories/Hospital%20Discharge%20final%20version.pdf](http://www.adass.org.uk/images/stories/Hospital%20Discharge%20final%20version.pdf)
- <sup>37</sup> Framework for the Assessment of Children in Need and their Families (2000). Accessed via: [www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4014430.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4014430.pdf)
- <sup>38</sup> UN. *Convention on the Rights of a Child*. Accessed via: [www.unicef.org/crc/](http://www.unicef.org/crc/)
- <sup>39</sup> GMC. *0-18 years: Guidance for all doctors* (2007). Accessed via: [www.gmc-uk.org/static/documents/content/0-18\\_0510.pdf](http://www.gmc-uk.org/static/documents/content/0-18_0510.pdf)

# Organising your practice to support carers

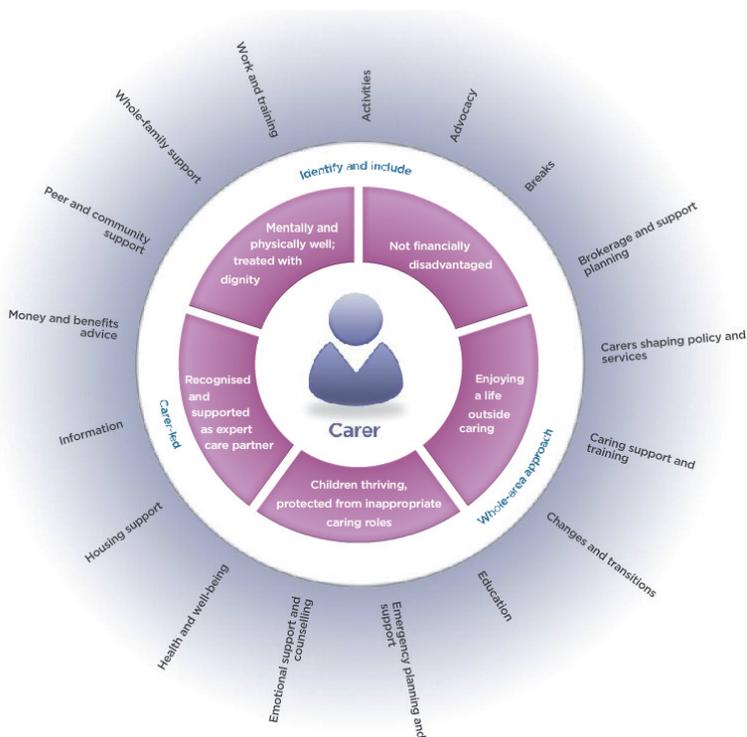
2.1 Carers' leads	20
2.2 Finding and recognising carers	20
2.3 Involving carers in patient care	23
2.4 Improving healthcare for carers	25
2.5 Information and support for carers	28
2.6 Supporting young carers	30
2.7 Auditing carer support	32



## 2.1 Carers' leads

Experience shows that in primary care it can be easier to make improvements for carers with someone to champion their cause within a GP practice. Identifying and supporting carers cannot be done on an individual basis: a whole team approach is needed. A carers' lead provides information and co-ordinates the team effort to provide the 'all-round' support that carers need (Figure 2.1.1).

**Figure 2.1.1: The Carers' Hub**



*Reproduced with kind permission from The Princess Royal Trust for Carers and Crossroads Care ([www.carershub.org](http://www.carershub.org))*

Anyone with an interest in carers and the issues that they face can be appointed 'Carers' Lead'. This may be a role taken on by a member of the clinical staff such as a GP or practice nurse, but it could be equally well performed by a member of the reception or administrative staff.

### Tasks that a carers' lead might undertake

- Be an in-practice contact point for carers
- Maintain the carer register
- Monitor carer numbers and explore ways that the practice might identify more carers
- Develop links between the practice and local carer support services both in the state and voluntary sectors
- Source information for carers that can be provided by the practice
- Explore ways the practice might support carers better and produce a carer support policy
- Keep colleagues up to date with developments in carer support at a local and also national level
- Audit practice activity to support carers e.g. using the self-assessment checklist produced by the RCGP and The Princess Royal Trust for Carers
- Seek the views of carers about how the practice is currently supporting carers and how it might improve support in the future.

## 2.2 Finding and recognising carers

It is difficult to identify carers as anyone can be a carer and people move in and out of caring roles according to their circumstances. Carers do not have any defining features that make them stand out from a crowd, and the person that the carer is caring for may not even be registered with your practice; 50% of carers look after someone who does not live with them<sup>40</sup>.

Key ways in which carers can be identified are listed below but this is not the job of the GP alone. Identifying carers is an activity in which the whole practice team is involved and staff who are the first point of contact, such as receptionists, are crucial.

Be careful with the term carer, as many carers do not consider themselves as such. Carers not known to you are more likely to come forward if a description of what is meant by the term is included and some practical help is offered, such as an information pack, or access to benefits advice.

### At registration

Most practices have a new patient questionnaire to collect basic information about newly registered patients. You could ask whether individuals are carers in your new patient questionnaire. As many carers do not consider themselves carers, rather than asking 'Are you a carer?' ask: 'Do you look after a sick, disabled or frail relative or friend without payment?' Consider enquiring about young carers too with a question such as: 'Is there a child or young person in the family who helps to provide care or support to another family member?'

### Self-identification

Inviting carers to notify you about their caring role can be a useful way to identify carers, particularly if the carer is registered with your practice, but looks after someone with care needs registered with another practice. You could also invite people who have carers to tell you who their carers are.

You could put posters in the reception area and waiting room, and a notice in the practice leaflet and/or newsletter inviting carers to identify themselves and people with care needs to tell you who their carers are. Consider including information in languages other than English to identify hard-to-reach carers too.

### Flu vaccination

The annual flu vaccination campaign is a good time to encourage carers to identify themselves. Carers are considered a priority group for annual influenza vaccination. You could:

- Highlight that carers can ask for vaccination on publicity posters.

- Mention that carers can request a flu vaccination in the practice newsletter.
- Include an invitation for carers to come for vaccination on letters sent to priority groups.

### Opportunistically

In primary care, you encounter carers every day of the week. It is very common for carers to call and make appointments for patients. It is also common for them to manage repeat prescription requests. They may bring patients to appointments and often arrange to be present if home visits are made. You could:

- Ask reception staff to make a note of who requests repeat prescriptions, appointments and home visits for people with mental health or substance misuse problems, and sick, frail, elderly, or disabled patients.
- Look at who brings such patients to surgery appointments and ask if they are the carers.
- Note who else is there when visiting a patient's home. Are they carers? Remember that anyone can be a carer including children and non-family members.

### List searches

Patients with certain conditions often have carers. Common examples include:

- Stroke
- Parkinson's disease
- Dementia
- Learning disability
- Severe mental illness

You could do a list search for patients with these conditions. If a carer cannot immediately be identified, then further investigation (for example by asking the patient, or looking who else is registered at that address) may identify new carers.

### At diagnosis, hospital discharge, or on hospital referral or admission

When a person has a new diagnosis added to his or her notes, or if a patient is discharged from hospital with a diagnosis that means that the

patient is likely to need a carer, flag this and try to find out who the carer is. You could:

- Call that patient's home and ask, or flag the patient's notes so that the person who next sees that patient remembers to ask.
- Look at who else lives at the same address as the patient, as many people are looked after by co-habitant relatives.
- Ask who the person's carer is and include this information in your letter for the hospital when admitting a person to hospital, or referring that person for specialist review. As well as recording this information in the referral letter, ask if you can record it in the patient's and carer's GP notes.

### Carer's organisations

In many areas, carer support organisations have close links with GP practices. If close links exist, carer support organisations may (with the carer's and patient's permission) liaise with GP surgeries about carers. This may be another way to identify carers previously unidentified in the practice.

### Carers from "hard to reach" groups

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).
- Those caring for people with mental health and/or substance misuse problems.
- Disabled carers.

To help identify carers from these groups, review your equalities policy and how it is implemented. Making links with community groups representing hard-to-reach groups may also identify previously unrecognised carers.

## Practice-based carers' support in West Sussex

The Carers Development Worker (Primary and Community Care) project at Carers Support Service, Worthing & District (a network member of The Princess Royal Trust for Carers) has had a dramatic effect on the numbers of carers identified by GP practices. One full time equivalent Carers Development Worker based at the service works with 34 GP practices across 43 sites. The project:

- Identifies a link person in each practice.
- Completes a detailed annual monitoring tool with each practice.
- Provides carer awareness training, information and support for all practice staff.
- Promotes healthy living practices at carers' events.
- Participates in multi-disciplinary meetings at GP practices where available.
- Ensures that GPs work to the GMS contract (Management Indicator 9).

Further information: [www.carerswsx.org.uk](http://www.carerswsx.org.uk)

### Young carers

*"I quite often go in with my mother when she goes to the doctor, but they still don't recognise the fact that I'm a young carer and still don't pay attention or give time to that matter."*

Young carer<sup>41</sup>

Young carers can also be particularly hard to identify:

- The child's caring role may not be recognised by the child or the child's family; many children grow into their caring role and know nothing different.
- Professionals involved with the family (such as GPs, social workers and school teachers) may be unaware of the child's role as the child may be at school when the person cared for is seen.

- Families may be very wary of involvement of formal support services with their children.
- Children may not want to declare their role for fear of being 'labelled' as different by their peers or being stigmatised by the condition that the person that they care for has.

Remember that *all* the children identified as living with an adult with a long-term condition that affects their ability to care for themselves, or as siblings of a child with a chronic disease or disability, are *potentially* young carers. Once families with potential young carers have been identified, it is important to establish what care tasks are performed and by whom before deciding if a child is a young carer, and whether the child has inappropriate caring responsibilities.

### Recording carer status

Once carers have been identified, record the carer's identifying and contact details on the patient records (if the patient is registered with your practice) with the patient's and carer's consent. In addition, record carer status on the carer's own records (if registered with your practice) with the carer's consent, thereby adding the carer to your practice carer's register. Specific Read codes are available for doing this (Table 2.2.1), and also for recording that carers are no longer providing care.

**Table 2.2.1 Read codes for carers**

Read code	Meaning
918F.00	Has a carer
918I.00	No longer has a carer
918G.00	Is a carer
918f.00	Is no longer a carer
8HkB.00	Referral for social services carer's assessment

### Useful questions to ask families with potential young carers<sup>42</sup>

- Who helps to care for the person needing care at home?
- What effect do the condition and personal care needs of the person requiring care have on the family?
- Is there a child/young person in the family who helps to provide care or support? If so, which tasks do they do?
- How does this affect the child/young person physically, emotionally or educationally?
- Do the parents need more support in their parenting role?
- What can be offered to help the whole family?

## 2.3 Involving carers in patient care

*"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."*

Carers know the people that they care for better than anyone else. This knowledge can be extremely useful in planning and implementing patient care, and also in identification of problems that may require intervention. However, many carers feel that they are not recognised as partners in care. Addressing the issues below will help to involve carers fully.

### Confidentiality

*"Her GP won't 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 carers in their caring roles.

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 ([www.rcpsych.ac.uk/PDF/Carersandconfidentiality.pdf](http://www.rcpsych.ac.uk/PDF/Carersandconfidentiality.pdf))

In some cases, patients lack the mental capacity to make a decision about sharing their personal information with carers. Under the terms of the Mental Capacity Act (2005), there should be a presumption that a person is able to make decisions independently unless there is good reason to believe otherwise. In order to demonstrate decision-making capacity a person should be able to:

- Understand the information relevant to that decision.
- Retain that information for long enough to make a decision.
- Use or weigh that information as part of the process of making that decision.
- Communicate his or her decision using verbal or non-verbal communication.

If a person is deemed to lack capacity, then his or her *best interests* should be acted upon. Consider the views of family and friends where practicable. In most cases, it is in the patient's best interests to share necessary information with the patient's

## How GPs and other health professionals can make a 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.
- Whenever care for a patient is being planned, where possible ask carers first about any problems that they may be having and their views about the best course of action to support the patient.
- Where a patient is reluctant for all information to be shared, talk through the consequences of this decision; there may be some aspects of their condition about which they are comfortable for information to be shared.
- Where patients do not want any information given to their carers, 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.
- Ask the carer to feedback any difficulties encountered once a new care plan has been instituted.

carer. Some people may have a Personal Welfare Lasting Power of Attorney (LPA) in place. As long as this is registered, the person named as the 'Attorney' has the right to make decisions about healthcare.

## Information sharing

Whenever you are planning care for a patient with a carer, where possible ask carers first about any problems that they may be having and their views

about the best course of action to support the patient. If permission has been given by the patient for personal information to be shared with the carer, discuss any care plan proposed with the carer and ask for the carer's views and feedback before implementing that plan. Finally, in all cases ask the carer to feedback any difficulties encountered once a new care plan has been instituted.

## Carer training

Through statutory and voluntary organisations, carers can access training on topics such as first aid, moving and handling, and stress management. They can meet other carers in support groups or receive one to one support from trained workers, including counselling. Carers can get help with applying for benefits that may help reduce financial concerns that cause stress, or even receive respite breaks giving them a much-needed break.

Carers Direct runs online self-study learning programmes to help carers in their caring role ([www.nhs.uk/CarersDirect/carers-learning-online](http://www.nhs.uk/CarersDirect/carers-learning-online)).

The programmes aim to help carers to:

- Understand how the care system works.
- Understand how caring affects their life and enable them to balance their commitments and manage their time and finances more effectively.
- Communicate more effectively with the person that they care for as well as health and social care professionals.
- Understand the emotions that they may experience in caring and find practical ways to deal with these emotions.

Specialised training may also be provided by the primary care team where needed. For example, carers perform many nursing tasks for which nursing professionals are trained. Consider asking the community nursing team to provide training for carers to carry out nursing tasks such as applying dressings or emptying/changing catheter bags.

**The Princess Royal Trust for Carers has 144 Carers' Centres in its UK network, including 85 young carers' services. Each Carers' Centre delivers a wide range of services including:**

- Finding hidden carers via outreach in GP surgeries, hospital wards and schools.
- Finding the right information for every carer, whatever their circumstances.
- Making sure carers' voices are listened to by local decision makers.
- Supporting carers emotionally and practically throughout their caring journey.
- Helping to make caring a positive experience by helping carers to share experiences, ensuring access to breaks, education, training and employment.

*Find your nearest Carers' Centre at [www.carers.org](http://www.carers.org)*

Medication is another issue that can cause problems for carers. Many are anxious about the responsibility that they take on when administering patient medication. Consider providing training for the carer about the medications being issued to the patient, their beneficial effects and possible side effects. Medication charts may help, as may pre-filled medication boxes (e.g. Nomad trays).

## 2.4 Improving healthcare for carers

Carers tend to neglect their own health. Sometimes this is because of practical reasons, for example they may not be able to leave the home to attend GP or specialist appointments, or for hospital treatment. Sometimes it is because carers focus so much on the care of the people that they are looking after that

they simply pay no attention to their own health needs. Whenever you see a carer with a patient, it is always worth asking the carer how he or she is. This may alert you to carer health problems, which you may be able to act on if the carer is your patient too. However, even if the carer is not your patient, a simple question such as this will make carers feel that they have been noticed and that you care about their welfare too.

## Depression screening

Remember that around 40% of carers experience significant psychological distress. Consider using a tool such as the National Institute for Health and Clinical Excellence (NICE) depression screening questions (Box 2) to screen for depression at least once a year<sup>43</sup>. A positive response to one or both of the screening questions should trigger further exploration of the carer's mood, for example using the Patient Health Questionnaire (PHQ-9) questionnaire.

### NICE screening questions for depression<sup>42</sup>

1. *During the last month, have you often been bothered by feeling down, depressed or hopeless?*
2. *During the last month, have you often been bothered by having little interest or pleasure in doing things?*

If the response to either of these questions is 'yes', further evaluation is warranted using a tool such as the Patient Health Questionnaire (PHQ-9).

## Appointment systems

Carers may have difficulty leaving the person that they care for to attend GP appointments. It is important to offer some flexibility for carers:

- Arrange appointments at times in the day when carers can leave the people that they care for

e.g. when paid care workers are in the home.

- Consider offering carers first appointments to minimise waiting time in the surgery.
- If carers bring the person that they care for to surgery appointments, consider offering consecutive appointments so that they can be seen at the same time.
- Try to do as much as possible in a single encounter to reduce the number of appointments that carers need to attend, for example opportunistic flu vaccination or chronic disease management checks when the carer comes in for another problem.

For some carers it may be impossible to leave even for a short time to attend GP appointments. Although these carers would not usually meet the criteria for a home visit as they are not themselves housebound, consider offering a home visit if the carer requires medical care.

## Flu vaccinations

All carers are entitled to a free annual influenza vaccination.

- Encourage carers on your carer register to attend for vaccination with personalised invitations.
- For patients being vaccinated at home by the community nursing services, consider asking if the carers can be vaccinated at the same time.
- Put a notice up in the practice inviting carers to attend for influenza vaccination and also include information about immunisation for carers in the letters inviting patients from priority groups for vaccination. This may also reveal new carers that you were not aware of previously.

## Other in-practice carer services

Some practices offer additional services for carers. Examples include annual health checks for carers, in-practice clinics run by carers' organisations for carers, and referral schemes for members of the primary care team to refer carers to the local carer centre for support and advice.

## Northamptonshire GP practice carer assessment and support worker service

A team of 7 carer assessment and support workers from Northamptonshire Carers work with GP practices to identify and support carers. The team were part of a pilot project funded by the Department of Health, and have subsequently been funded through to March 2012 by the PCT.

### *Benefits to carers include:*

- A listening ear.
- Information and advice.
- Support.
- Signposting to other services such as Carer Support Groups and carers' breaks.
- Encouragement to take care of own health needs.
- Access to a carer's assessment.
- Help with accessing benefits.

### *Benefits to GP surgeries include:*

- A clear referral pathway to effective carer support.
- An additional resource to meet patient needs.
- Help with early identification of carers' own health problems.
- Promoting and sharing good practice.
- Increased carer awareness.
- Cost efficiency through promotion of carer health; crisis prevention; reduction in repeated and missed appointments; reduction in unplanned hospital admissions and secondary care referrals

*"The team has shown us how easy it is to refer clients. They have been instrumental in helping us to identify carers and their potential needs. They have given us help in directing carers to the most appropriate people to help them. They keep us updated with new and continuing events and information. We have made constructive changes (with their help) to the way we record carers and the person they care for to help us offer a better service."*

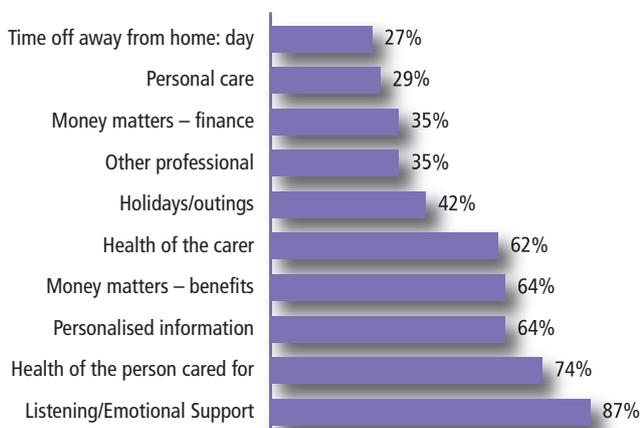
*Further information: e-mail [hwright@northamptonshire-carers.org](mailto:hwright@northamptonshire-carers.org)*

## 2.5 Information and support for carers

*"I think one of the problems is that you don't know what is available and you don't get things without asking for them – like the transport. If you don't know it's there how can you ask for it? We're lucky – we are quite able – if you were older or not so capable it would be very difficult to get what you needed."*<sup>44</sup>

Figure 2.5.1 shows priority issues for carers. Clearly the primary care team cannot give expert advice on all these matters. The role of the GP and primary care team is to identify issues of concern to carers, deal with them where possible, and otherwise signpost carers to appropriate medical, social and voluntary services to support them.

**Figure 2.5.1 Priority issues for carers: top ten needs of 2360 carers supported in general practices in Airedale (2006-2011)**



*Reproduced with kind permission from Carers' Resource (Harrogate and Craven, Bradford and Airedale) funded by NHS Bradford and Airedale (formerly Airedale PCT) to provide specialist carer support in primary care settings.*

### Carer support organisations

Carer centres and other services for carers provided by carers' charities are a very valuable source of help and support. National carers' charities are listed in Box 2.5.1 together with their

contact details. There are also many very helpful local charities that provide support to carers. Find out which carer charities operate in your practice area and how to contact them.

In areas where there is no specialist carers' centre, PCTs (or successor bodies) may decide to commission new services. Contact Carers UK or The Princess Royal Trust for Carers for advice and support, consider ways to audit local carers support and find out about good practice models at [www.carershub.org](http://www.carershub.org).

#### Box 2.5.1 Support for carers

- Carers Direct Helpline: 0808 802 0202  
Website: [www.nhs.uk/carersdirect/Pages/CarersDirectHome.aspx](http://www.nhs.uk/carersdirect/Pages/CarersDirectHome.aspx)
- Directgov Website:  
[www.direct.gov.uk/carers](http://www.direct.gov.uk/carers)
- The Princess Royal Trust for Carers  
Website: [www.carers.org](http://www.carers.org)
- Carers UK Website: [www.carersuk.org](http://www.carersuk.org)
- Crossroads Care Website:  
[www.crossroads.org.uk](http://www.crossroads.org.uk)
- Citizens Advice Bureau Website:  
[www.adviceguide.org.uk](http://www.adviceguide.org.uk)

### Other sources of information and support

In addition to information provided by carers' charities, the Department of Health's NHS website 'Carers Direct' (Box 2.5.1) provides information and educational resources for carers and health professionals about carers' issues. The Directgov website (Box 2.5.1) provides information on all aspects of caring including employment, carers' rights and benefits. The Citizen's Advice Bureau also provides information for carers on carers issues, and on benefits, debt and employment issues, both through its website (Box 2.5.1) and through its local offices. Finally, condition-specific organisations (such as The Stroke Association,

Parkinson's UK, The Alzheimer's Society and Mind) also provide excellent condition-specific information, and more general support, for both patients and carers.

### **Dementia Cafe – Crossroads Care, Richmond**

Crossroads Care Richmond in partnership with the Alzheimer's Society, with support from Richmond NHS and the London Borough of Richmond upon Thames, 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 provides respite, advice and support, social opportunities and activities to tackle isolation. Transport is provided when needed. Should carers want to take time out for an hour or so, for example to attend support groups, or visit the shops, there is provision to care for 10 people with dementia within the café.

*Further information: e-mail*

*[richmonduponthames@crossroads.org.uk](mailto:richmonduponthames@crossroads.org.uk)*

## **Benefits**

Consider:

- Benefits for the person being cared for e.g. Employment Support Allowance (ESA), Disability Living Allowance (under 65's) or Attendance Allowance (over 65's).
- Benefits for those on low income e.g. Income Support, Housing Benefit, Council Tax Reduction, Social Fund Payments.
- Benefits for carers- carers aged over 16 can receive a Carer's Allowance of £55.55 per week (2011/12 figures) if they are caring for more than 35 hours per week and meet other criteria.

Carers of a relative, partner or somebody living at the same address also have the right to request flexible working and employers must consider this.

Local Carers' Centres or other carers' organisations, the Citizens Advice Bureau or Carers' Direct advise about benefits and may help to make an application.

### **Carers' Support (Bexley): Welfare Benefits Advice Service**

Carers' Support Bexley's welfare benefits advice service is managed by an experienced welfare benefits advisor. When a carer first contacts the Centre, he or she is offered a welfare benefits "check". If the service identifies that there are benefits that the carer or cared for person can claim, a worker will arrange to meet with the family to complete the forms. The service manager also holds welfare benefits "surgeries" at the offices of other voluntary organisations and gives talks to groups of carers and professionals to raise awareness about entitlements, and carers' issues in general.

The Centre is registered as an "Alternative Office" with the Department of Work and Pensions (DWP). This means that the service manager can verify documents (rather than sending them to the DWP) and date stamp claim forms, so that the person's date of claim becomes the date that the Centre is first contacted.

Further information: [info@carerssupport.org](mailto:info@carerssupport.org)

## **Social services carer assessments**

Adult carers providing "regular and substantial" care have a right to an assessment of their needs. "Regular" and "substantial" have not been defined in law to allow flexibility when judging whether a carer should have the right to assessment. All carers who provide a regular and substantial amount of care are entitled to (and should) request a carer assessment in their own right from social services.

The carer assessment is designed to assess the carer's needs and not the needs of the person

that the carer is caring for. If there is more than one person providing care in a household, each is entitled to a carer assessment.

As a result of the assessment the carer should receive a care plan that takes into consideration the assessed needs of both the carer and the person being cared for. It may include respite care, help with housework, changes to equipment or adaptations to the home, and/or emotional support. If anything changes, the carer is entitled to apply for a re-assessment.

The Quality and Outcomes Framework (QOF) includes an indicator (Management 9) which relates to referral of carers for social services assessment: 'The practice has a protocol for the identification of carers and a mechanism for the referral of carers for social services assessment'<sup>45</sup>.

*"I don't get any day breaks you know where I can go out and leave him, not for long. Well I must say they have offered it so yes they said if I need it I am entitled to it. I was hoping to do it when they were building this bathroom, but he didn't want to go so I didn't push it as he hadn't been very well, but hopefully I will get a break eventually. It's just that it is tiring, you know continually doing."*<sup>46</sup>

### Emergency planning

Emergency planning should be part of the local authority carer's assessment. New legislation means that carers should now be able to lodge emergency plans in a database. They are then provided with a card to carry in their wallet or purse so that if there is an emergency, anyone finding the card knows that the person is a carer. The card has a number on it to enable the carer or anyone finding the card to ring and trigger the 'Action Plan' to provide emergency substitute support. Contact local carers' organisations and social services departments for further information.



## 2.6 Supporting young carers

When supporting and signposting young carers identified in primary care, it is important to provide a *whole family approach*, looking at support not only for the young carer, but also for the person being cared for and other family members.

### Ways to improve support for young carers within your practice

- Raising awareness about young carers amongst all the staff in your practice; training may be available via local Young Carers Services.
- Consider nominating one member of staff to be a carers' champion to act as a link to agencies in your local area that offer support to young carers and their families.
- Find out if there is a local *Young Carers Service* or if support is offered in schools.
- Use the notice board in your waiting area to promote sources of support for young carers and their families.

*Information which can be used by GP surgeries is available from the Professionals section on [www.youngcarer.com](http://www.youngcarer.com)*

### Involving the child's school

Find out if the child's school is involved or aware of what is happening to the child and the caring role that the child has taken on. Do they, or could the child's school, offer sensitive support? Discuss this with the young carer and family. If the young

carer and family are in agreement, contact the school nurse for help, or find out if the child's school has a lead teacher to support young carers and contact that teacher.

### **Assessment for the person with care needs**

Young carers perform their caring roles because of unmet care needs, but no care package should rely on the inappropriate caring role of a child.

Consider contacting the local Adult Services Department and referring the family member who has care needs for an assessment of needs under the NHS and Community Care Act 1990.

Disabled parents may value support to enable them to carry out their parenting role. The Disabled Parents Network provides useful information and support (Box 2.6.1).

'The Whole Family Pathway' is an online resource signposting practitioners to support available for families<sup>47</sup>. It is also a useful map for families to follow to inform their choices.

### **Assessment for young carers**

Like adults, young carers are entitled to referral for a carer's assessment. Consider referring the young carer to the Children's Services Department for an

## **Box 2.6.1 Information and support for young carers**

### *General support*

- The Princess Royal Trust for Carers. Website: [www.carers.org](http://www.carers.org); YCNet for young carers. Website: [www.youngcarers.net](http://www.youngcarers.net)
- The Children's Society Include Project. Website: [www.youngcarer.com](http://www.youngcarer.com) ; A-Z Listing of Young Carer Projects: [www.youngcarer.com/showPage.php?file=projects.htm](http://www.youngcarer.com/showPage.php?file=projects.htm)
- NHS Carers Direct. Tel: 0808 802 0202. Website: [www.nhs.uk/carersdirect/young/Pages/Youngcarershome.aspx](http://www.nhs.uk/carersdirect/young/Pages/Youngcarershome.aspx)
- Direct.gov. Website: [www.direct.gov.uk/en/CaringForSomeone/CaringAndSupportServices/DG\\_4000194](http://www.direct.gov.uk/en/CaringForSomeone/CaringAndSupportServices/DG_4000194)
- Carers UK. Website: [www.carersuk.org](http://www.carersuk.org)

### *Information and support for children*

- NHS Children First. Age-specific health information for children. Website: [www.childrenfirst.nhs.uk](http://www.childrenfirst.nhs.uk)
- Information on mental health issues designed for young people. Website: [www.youngminds.org.uk](http://www.youngminds.org.uk)
- Information and support for children caring for someone with cancer. Websites: [www.riprap.org.uk](http://www.riprap.org.uk) or [www.macmillan.org.uk/Cancerinformation/Ifsomeoneelsehascancer/Youngcarers2010.aspx](http://www.macmillan.org.uk/Cancerinformation/Ifsomeoneelsehascancer/Youngcarers2010.aspx)
- Information and support if a sibling has special needs, chronic illness or a disability. Websites: [www.sibs.org.uk](http://www.sibs.org.uk) or [www.cafamily.org.uk](http://www.cafamily.org.uk)
- Information about drug and alcohol issues. Websites: [www.adfam.org.uk](http://www.adfam.org.uk) , [www.nacoa.org.uk](http://www.nacoa.org.uk) , [www.starsnationalinitiative.org.uk](http://www.starsnationalinitiative.org.uk) or [www.talktofrank.com](http://www.talktofrank.com)

### *Disabled parents*

- Disabled Parents Network. Website: [www.disabledparentsnetwork.org.uk](http://www.disabledparentsnetwork.org.uk)

### *Bereaved children*

- The Cruse Bereavement Care Youth Involvement Project (RD4U). Website: [www.rd4u.org.uk](http://www.rd4u.org.uk)
- Winston's Wish. Website: [www.winstonswish.org.uk](http://www.winstonswish.org.uk)

assessment under the Common Assessment Framework. A young carer assessment should automatically trigger a community care assessment or review of the person being cared for.

Some young carers and their families are reluctant to admit the child's role as a carer and are fearful of seeking help from social services, but would value sensitive support. Contact your local Children's Services Department for advice, keeping the identity of the family anonymous to protect confidentiality.

If the young carer is caring inappropriately or coming to any significant harm as a result of caring duties, or is in danger or being neglected as a result of a family member's illness, then you must take action, even if the family refuses help. Under the 1989 Children's Act, it is *compulsory* to refer to the Children's Services for an assessment if you feel that a child is 'in need' or 'at risk', with or without the consent of the parent(s). However, it is not always easy to decide if a young carer is 'in need' or 'at risk'. If you are unsure what to do, consider contacting your local children's safeguarding lead for advice.

## Young Carer services

Young Carer Services provide specialist advice and support for carers under the age of 18. Always consider referring any young carer identified to your local service. A full list of local Young Carer Services is available at [www.youngcarer.com](http://www.youngcarer.com).

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](http://www.youngcarers.net).

## Information provision

Age-appropriate information can be helpful for young carers. Address any worries the young carer

may have. A list of useful websites is included in Box 2.6.1. The NHS Children First website (Box 2.6.1) provides health information designed for children. Some of the questions that trouble young carers include:

- Can I catch it? Will it happen to me too?
- What caused it? Why us? Is it my fault?
- Can I do anything to make it better?
- Will the person that I look after get worse or die?
- What should I do in an emergency?

*"A major worrying task is that most young carers are responsible for giving out medication to the person they care for.... They were worried that one mistake could be fatal."*

R Morgan (2006)<sup>48</sup>

When prescribing medication for any patient, always consider whether a young carer may be administering it. Is that appropriate? Does the young carer and/or family need support? Try to find ways of relieving the young carer of this responsibility or consider providing training for the young carer if appropriate.

## 2.7 Auditing carer support

Audit is a continual process and an essential and integral part of clinical governance. Its purpose is to appraise current practice (*What is happening?*) by measuring it against pre-selected standards (*What should be happening?*), and to identify and implement areas for change (*What changes are needed?*).

Auditing carer support is essential to ensure that the practice is meeting the needs of its carers.

Several types of audit may be effective:

**Carer surveys and focus groups** – these are good ways to obtain 'users' views' about the

service provided by the practice for carers and suggestions for improvements that could be implemented.

**Criterion-based audit** – involves comparing practice performance against pre-agreed standards. As a result of this process, any changes deemed necessary should be implemented and then the audit cycle should be repeated to assess effectiveness of the changes and identify new areas of practice in which improvements might be made: the so-called ‘audit cycle’. This Action Guide contains a self-assessment checklist which can be used to determine the criteria on which to build a criterion-based audit of carer support.

**Adverse occurrence screening and critical incident monitoring** – this is often used to peer review cases which have caused concern or from which there was an unexpected outcome. The multidisciplinary team discusses individual anonymous cases to reflect upon the way that the team functioned and to learn for the future. In the primary care setting, this is described as a ‘significant event analysis’. Collapse of a caregiving situation would be a good topic for significant event audit.

<sup>40</sup> NHS Information Centre for Health and Social Care. Survey of carers in households 2009/2010 (2010b). Accessed via: [www.ic.nhs.uk/webfiles/publications/009\\_Social\\_Care/carersurvey0910/Survey\\_of\\_Carers\\_in\\_Households\\_2009\\_10\\_England.pdf](http://www.ic.nhs.uk/webfiles/publications/009_Social_Care/carersurvey0910/Survey_of_Carers_in_Households_2009_10_England.pdf)

<sup>41</sup> Frank J. Making it Work. Good practice with young carers and their families (2002). London: The Children's Society and the Princess Royal Trust for Carers.

<sup>42</sup> The Children's Society Include Project. *Supporting young carers and their families: Information for healthcare professionals* (2010)

<sup>43</sup> NICE. *Depression: Treatment and management of depression in adults, including adults with a chronic physical health problem* (2009) Accessed via: <http://guidance.nice.org.uk/CG90/QuickRefGuide/pdf/English>

<sup>44</sup> Simon C, Little P, Birtwistle J, Kendrick T. A questionnaire to measure satisfaction with community services for informal carers of stroke patients: construction and initial piloting. *Health and Social Care in the Community* (2003) 11(2) pp.129-137

<sup>45</sup> BMA/NHS Employers. *Quality and Outcomes Guidance for GMS Contract 2011/12* (2011). Accessed via: [www.nhsemployers.org/SiteCollectionDocuments/QOFGuidanceGMScontract\\_2011\\_12\\_FL%2013042011.pdf](http://www.nhsemployers.org/SiteCollectionDocuments/QOFGuidanceGMScontract_2011_12_FL%2013042011.pdf)

<sup>46</sup> Simon C, Little P, Birtwistle J, Kendrick T. A questionnaire to measure satisfaction with community services for informal carers of stroke patients: construction and initial piloting. *Health and Social Care in the Community* (2003) 11(2) pp.129-137

<sup>47</sup> The Children's Society/Princess Royal Trust for Carers/Disabled Parents Network. *The whole family pathway: A resource for practitioners* (2008). Accessed via: [www.youngcarer.com/pdfs/Whole%20Family%20Pathway%2010th.pdf](http://www.youngcarer.com/pdfs/Whole%20Family%20Pathway%2010th.pdf)

<sup>48</sup> Children's Rights Director for Commission for Social Care In: *Being a young carer. Views from a Young carer's Workshop* (2006)

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## Developing your Practice Action Plan



## Self-Assessment checklist

### Audit standard

#### Carers lead

Does your practice have a carers' lead? Yes  No

#### Identification of carers

What is the percentage of expected carers on your practice list included on your practice register?  %

Does your practice have a policy in place to encourage carers to self-identify? Yes  No

Does your practice have a policy in place to proactively identify carers? Yes  No

Does your practice have mechanisms in place to code carer status? Yes  No

#### Involving carers in patient care

Is informed consent routinely sought from patients to share their health information with carers? Yes  No

Does your practice have a policy to involve carers in care planning and implementation? Yes  No

Have all carers on your carer register been offered training to perform their roles? Yes  No

#### Healthcare for carers

What is the percentage of carers on your carer register who have had a depression screen in the past year?  %

Is there a policy in place that allows carers to arrange routine GP appointments or home visits at times when it is convenient for them? Yes  No

Are all carers on the practice carer register routinely offered flu vaccinations? Yes  No

#### Information and support

Does your practice keep an up-to-date list of the contact details of organisations that can provide information and support to carers? Yes  No

#### Social services carer assessments

What percent of carers on your carer register have a referral for a social services carer assessment recorded in their notes?  %

What percent of carers on your carer register have an emergency plan in place?  %

#### Young carers

Does your practice have a policy in place to identify and support young carers (i.e. those under the age of 18)? Yes  No

### Notes

Number of expected carers = list size ÷ 10  
Target: >50% included on register

What is that policy?  
How could it be improved?

What is that policy?  
How could it be improved?

E.g. when carers are identified or stop being carers.

How is this done and recorded?

What is that policy?  
How could it be improved?

What training is offered?  
How could this be improved?

$(\text{Number screened} \div \text{total number of carers}) \times 100$

What is that policy?  
How could it be improved?

When was the list last checked to ensure that the details were still correct?

$(\text{Number referred} \div \text{total number of carers}) \times 100$   
Target >80%

$(\text{Number referred} \div \text{total number of carers}) \times 100$   
Target >80%

e.g. information aimed at young carers; information about young carer centres; mechanism for referral for social services assessment and/or further support.  
What is that policy?  
How could it be improved?

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