



Royal College of
General Practitioners

Involving and Supporting Carers and Families

An educational framework and learning
resource for GPs and primary care teams

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Contents

About this document	4
Key messages	5
Putting professional capabilities into practice.....	6
Theme 1: Knowing yourself and relating to others	6
Theme 2: Applying clinical knowledge and skill.....	9
Theme 3: Managing complex and long-term care.....	11
Theme 4: Working in organisations and systems	13
Theme 5: Caring for people and communities	15
Approaches to learning.....	17
1: The carer's role	18
2: The costs of caring	23
3: Involving carers and families.....	27
4. Improving services for carers.....	34
Useful learning resources	40
References	41

About this document

Involving and supporting carers and families is an educational tool to aid primary care practitioners, teams and educators. It contains recommended key messages and themes, together with case illustrations and other practical information. It provides an educational framework that is intended to help primary care educators and practitioners to plan and structure carer-related educational training, workshops, courses and other learning resources.

The project was developed with funding from the Department of Health and forms part of a wider programme of RCGP work '*Supporting carers in general practice*'. Separate resources for GPs, primary care practitioners and commissioners have been developed as part of the supporting carers programme. For further information, please visit www.rcgp.org.uk/carers.

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Key messages

- A carer is someone who, without payment, provides support to a partner, child, relative, friend or neighbour who could not manage without their help; 12% of adults in the UK are carers¹
- Carers and other family members suffer a range of health, social and financial consequences as a result of their role
- Although involving and supporting carers requires multidisciplinary input from the health and social services and the voluntary sector, primary care is often the initial point of access for carers
- Care provided by carers and other family members saves the UK economy in excess of £119 billion in care costs every year²
- It is important that primary care teams are aware of the problems that carers face, and practices are organised to identify carers, involve them in patient care where appropriate, and support them to maintain the caregiving situation.

Case illustration

Rosie is 18. The last time that she was seen in your surgery was nearly 4 years ago, even though she has been registered with you for over 10 years.

Rosie comes into the surgery very tearful. She tells you that she is struggling to cope with college and looking after her mother who is disabled following a nasty head injury two years previously. Her mother is also registered with your surgery but you do not see her frequently either, and you were under the impression that she was largely self-caring.

There are many ways in which you might help Rosie. These are suggestions and you may have further ideas:

- Record that Rosie is a carer on her medical record
- Find out exactly what Rosie is doing for her mother - does her mother need further medical assessment by you or social services assessment to provide additional care?
- Provide Rosie with information about being a carer and the support available for carers
- Refer Rosie for a social services carer assessment
- Consider referring Rosie for specialist support via a carers' organisation
- Consider putting Rosie in touch with organisations supporting people in the community who have had a head injury
- Suggest that Rosie speaks to her college tutor about the problems that she is having with her course and the reasons for this
- Monitor Rosie's low mood through regular review in the surgery, and provide medication and/or refer for specialist psychological support, as appropriate.

Putting professional capabilities into practice

The following section illustrates how the essential capabilities required of a NHS General Practitioner can be applied in everyday general practice to enable the involvement and support of carers and families. These capabilities are based on the generic capabilities currently being developed for the RCGP's enhanced curriculum for general practice.

Theme 1: Knowing yourself and relating to others

1.1 Demonstrate the attitudes and behaviours expected of a good doctor

For a GP who is proficient at supporting carers and families, this might involve:

- Listening to the concerns of carers and family members about the people for whom they care
- Respecting confidentiality of patients and seeking their permission (preferably in writing) before sharing confidential medical information with carers or family members
- Treating carers and other family members that help to look after your patient as members of the healthcare team
- Considering the carer's and family's perspective and, with the consent of the patient, involving carers and family members in management decisions wherever possible
- Involving the whole multidisciplinary health and social care team and voluntary sector when supporting families and carers
- Considering other staff members in your organisation who are carers and making allowances for the demands that are placed on them as a result of their caregiving roles

1.2 Identify the factors that influence your performance.

For a GP who is proficient at supporting carers and families, this might involve:

- Acknowledging that carers can be very hard to identify and many carers do not consider themselves as such; without being identified it is impossible to involve carers in patient care or support them in their caring roles
- Establishing ways to identify carers (for example, seeing who accompanies patients to appointments, or asking patients to self-identify) and flagging them on computer systems
- Identifying ways to manage the confidentiality issues that are often cited by GPs as reasons why they are unable to include carers in care decisions
- Seeking feedback from carers and family members of patients with chronic health problems about the support they receive from you and your practice
- Reflecting on your own approach and accessibility for carers; how could you improve this?
- Exploring the services available to support families and carers in your locality and thinking of effective ways to signpost carers to those resources

1.3 Treat others fairly and with respect, acting without discrimination.

For a GP who is proficient at supporting carers and families, this might involve:

- Considering how to engage with 'hard-to-reach' carers, such as those from the gay community, those from black and minority ethnic populations and young carers under the age of 18
- Relating to carers and family members as individuals, respecting their contribution to patient care and challenging negative attitudes towards carers

1.4 Establish an effective partnership with patients.

For a GP who is proficient at supporting carers and families, this might involve:

- Acknowledging to carers and other family members the important role they play in providing care for patients in the community
- Becoming proficient in consulting approaches that establish rapport with carers and other family members
- Developing a range of communication skills that can be tailored to different types of carers (for example, young carers or carers from different cultures or ethnic groups)
- Exploring the ideas, concerns and expectations of carers and other family members
- Co-ordinating and integrating the agendas of carers and other family members with that of the patient and your own agenda as the doctor, to enable shared decision-making and to negotiate an agreed management plan

1.5 Maintain a continuing relationship with patients, carers and families.

For a GP who is proficient at supporting carers and families, this might involve:

- Developing your skills for counselling, coaching, teaching and planning care with families and carers, recognising that continuity of care and effective long-term relationships are essential components of high quality care
- Involving carers, relatives and friends in decision-making, negotiating when and how to do this while preserving the patient's right to autonomy and confidentiality

1.6 Work as an effective team member within your organisation.

For a GP who is proficient at supporting carers and families, this might involve:

- Working effectively with a range of colleagues within and across the health, social care and voluntary sector systems, communicating well, passing on relevant information and using your and their expertise appropriately to support carers and families
- Monitoring the quality of accessibility and support for carers and families in your organisation and taking appropriate action to make improvements when needed
- Participating in the education and development of other team members about carers' issues

1.7 Apply leadership skills to improve quality, safety and effectiveness of care.

For a GP who is proficient at supporting carers and families, this might involve:

- Treating situations in which care in the community has broken down (e.g. because the carer or family was unable to cope) as significant events and exploring ways in which the carer and/or family could have been supported to continue caring
- Promoting a carer-friendly culture within your organisation to enable and support carers to look after their own health needs, despite their caring responsibilities (for example, by providing appointments for carers at times when they can leave the person they care for)
- Exploring the possibility of providing extended services for carers within your organisation, for example with a carers lead and/or input from a local carers organisation
- Considering services that are missing (or could be improved) for carers and families in your locality and lobbying your local primary care organisation or clinical commissioning group to provide/enhance those services

Theme 2: Applying clinical knowledge and skill

2.1 Provide appropriate clinical care to patients of all ages and backgrounds

For a GP who is proficient at supporting carers and families, this might involve:

- Offering carers consultations at times when their caring duties permit them to access the GP surgery (or home visits if they are unable to attend the GP surgery because of caring duties)
- Considering that carers may neglect their own health because they are too busy with their caring duties to worry about themselves (e.g. for fear of taking time out from their caring responsibilities or because they are worried that they may not be able to continue caring)
- Encouraging and enabling carers to have an annual influenza vaccination as a priority group

2.2 Adopt a proficient approach to diagnosis.

For a GP who is proficient at supporting carers and families, this might involve:

- Recognising that carers often know the people they care for better than anyone else and that information from carers about the symptoms of the person they are caring for may provide vital clues to diagnosis
- Knowing the epidemiology of conditions that affect carers; for example, around 40% of carers have high levels of anxiety or depression so consider screening carers for depression on an annual basis. Also, many carers' duties include heaving lifting which may predispose them to musculoskeletal injuries
- Recognising that young carers have a higher than average prevalence of self-harm; consider asking young carers about this in a sensitive manner

2.3 Adopt a proficient approach to clinical management.

For a GP who is proficient at supporting carers and families, this might involve:

- Providing adequate safety-netting and follow-up arrangements for carers and family members to reduce risk and to improve care
- Providing education for carers and family members about medicine management for the person that they are caring for
- Involving multidisciplinary team members to support carers and family members in providing care (e.g. asking the community nursing team to advise on catheter management or the community physiotherapist to advise on how to encourage mobility, etc.)

2.4 Apply a scientific and evidence-based approach to practice.

For a GP who is proficient at supporting carers and families, this might involve:

- Knowing the epidemiology relevant to carers including the number of carers in the UK, their age distribution and the problems they are known to face
- Knowing and addressing the problems most commonly associated with breakdown in the caregiving relationship (i.e. behavioural problems, communication problems and incontinence)

2.5 Provide your patients with appropriate access to the full range of care, according to need

For a GP who is proficient at supporting carers and families, this might involve:

- Referring people promptly and effectively to appropriate services when required
- Developing knowledge of where to obtain more information about the financial and social support for which people with long-term conditions and their carers may be eligible
- Exploring the local and national availability of self-help support groups for patients with long-term health problems and their carers, and signposting patients and carers to these organisations as appropriate
- Being an advocate and providing appropriate support to patients with long-term conditions and their carers when they are applying for resources or support from other agencies

Theme 3: Managing complex and long-term care

3.1 Provide care through the expected transitions of life.

For a GP who is proficient at supporting carers and families, this might involve:

- Understanding the natural transitions of the carers' pathway; from entering the caregiving role through maintaining caregiving responsibilities to loss of the caregiver role, as a result of bereavement or admission of the person being cared for into residential care
- Appreciating that carers may need different information and support depending on where they are on their caregiving pathway; consider providing or signposting carers to education about being a carer and also specialised advice or training for specific aspects of their role (e.g. advice about lifting and transferring the person they care for)
- Actively involving carers and other family members in both the planning and implementation of the long-term management plans of those they care for
- Helping carers and other family members to navigate the person they care for to appropriate services and team members in a timely and effective manner

3.2 Enable people living with long-term health conditions to thrive.

For a GP who is proficient at supporting carers and families, this might involve:

- Developing a working understanding of the concepts and approaches to managing multiple morbidity, treatment burden, survivorship, rehabilitation and recovery which should include support and involvement of carers and other family members
- Knowing the health effects of caregiving (including increased risk of cardiovascular disease and psychological distress), the social effects of caregiving (social isolation), the financial effects of caregiving (reduced income and increased costs) and the effects of caregiving on work and education and being pro-active in mitigating these risks

3.3 Manage concurrent health problems within an individual patient.

For a GP who is proficient at supporting carers and families, this might involve:

- Adopting a problem-based approach with carers to clarify the clinical and non-clinical issues that need to be addressed and identifying priorities in partnership, by using skills in problem identification, exploration, prioritisation, negotiation and shared decision-making
- Developing your ability to use the medical records and information tools to enhance, inform the document shared decision-making with patients, carers and multi-disciplinary teams (e.g. record when patients have a carer and who that carer is. Also record when patients are themselves carers)

3.4 Adopt safe and effective approaches for patients with complex health problems.

For a GP supporting carers and families, this involves:

- Using carers to help with complex problem-solving (e.g. they are often able to help you to prioritise or solve problems), to assist with safety-netting and to provide you with feedback when management plans are instituted
- Being alert to the complex relationships and interactions between patients and carers/other family members and how these relationships may affect complex health problems. For example, a carer's low mood might impact on the mood of the person being cared for
- Remaining alert to the risk of abuse, which is common in caregiving relationships. This may take the form of a carer abusing the person being cared for, but many carers also suffer abuse from the people that they care for, particularly if the person being cared for has behavioural problems

3.5 Coordinate a team-based approach to care for patients.

For a GP who is proficient at supporting carers and families, this might involve:

- Recognising the importance of organised and structured care planning involving carers and other family members as part of the multi-disciplinary team
- Considering how your patient's illness may be affecting his or her carers' health (from a medical, social and financial perspective)
- Identifying the implications for carers of any changes made to your patients' management plans

Theme 4: Working in organisations and systems

4.1 Understand the health service and your role within it.

For a GP who is proficient at supporting carers and families, this might involve:

- Recognising that a far greater proportion of carers have had contact with a GP than with any other health or social care professional (80-90% of carers will have had contact with a GP in the previous 6 months). This means that you serve as a key access point for carers to gain support for themselves and the people that they care for
- Appreciating that carers are a vital group to the functioning of the health economy (carers save the UK in excess of £119 billion every year in care costs, more than the entire health budget). Therefore it is important to support carers in their roles, both within practices and also more widely in the health system

4.2 Improve the quality of care you provide as a practitioner.

For a GP who is proficient at supporting carers and families, this might involve:

- Critically reflecting on the way that you and your practice support carers, for example by implementing the RCGP Carers Action Plan and/or doing the RCGP Carer Support Checklist Audit on an annual basis
- Examining barriers to carer support and ways in which they could be overcome within your field of practice (e.g. by developing a consent form for patients to sign to allow carers access to medical information about them relevant to their care and a method flagging that consent has been given to share medical information with named carers on patient notes)

4.3 Contribute to the improvement of the organisations and services in which you work.

For a GP who is proficient at supporting carers and families, this might involve:

- Using the information systems within your organisation to promote the identification of carers (e.g. include a question for people newly registering about whether the individual looks after anyone else with an illness or disability; invite carers for flu vaccination when annual flu vaccination letters are sent out; use practice newsletters to explain what carers do and encourage carers to self-identify to the practice, etc.)
- Putting together and providing an information pack for carers and family members to help them in their roles
- Regularly obtaining feedback from carers on your appointment booking, referral and communication systems and using these data to improve access and continuity of care

4.4 Work effectively and safely in integrated teams and services.

For a GP who is proficient at supporting carers and families, this might involve:

- Navigating carers across organisational, societal and professional boundaries, through planning, coordination and good communication
- Acknowledging that your duty of concern for your patients and their carers extends beyond organisational boundaries and spans across services (e.g. carers may have concerns that they would like to discuss with you even though the person that they care for is under ongoing follow up by a secondary care team)

4.5 Apply a safe and scientific approach to improving quality of care.

For a GP who is proficient at supporting carers and families, this might involve:

- Identifying the metrics that should be used to assess the quality of the support and healthcare you provide for carers, such as carer experience and health outcomes
- Adopting a planned and structured approach to implementing change to address healthcare inequalities for carers (e.g. resulting from limited access and difficulties addressing own health needs because of caring responsibilities), including identifying the restraining and driving forces to successful implementation and adopting collaborative approaches to address barriers
- Measuring the impact of the changes you make on carers and responding effectively to any unintended consequences

Theme 5: Caring for people and communities

5.1 Develop the mindset required of an expert generalist medical practitioner

For a GP who is proficient at supporting carers and families, this might involve:

- Demonstrate the ability to analyse, interpret and integrate relevant information from a diverse range of sources (e.g. narrative information, clinical findings, laboratory data) and modes of knowledge (e.g. verbal, intuitive and sensory data) in order to make more holistic judgements
- Recognise the importance of educational activities, formative assessment activities, feedback and reflection on revealing your patterns of thinking about carers, using these insights to improve the effectiveness and safety of your judgements

5.2 Apply a person-centred and holistic understanding of health to everyday practice

For a GP who is proficient at supporting carers and families, this might involve:

- Recognising that there are both positive and negative aspects of caring for someone with ongoing health problems and that carers will often have mixed emotions about their roles
- Appreciating that being a carer can have implications for all aspects of the carer's life, including physical health, mental health, relationships, other social interactions, employment, education and finances; all these factors will impact on carer wellbeing
- Valuing the views of carers and acknowledging the barriers that they face to providing effective support for the person they care for; appreciating that factors affecting a carer's health may affect his or her ability to care
- Helping carers and other family members to address the barriers they face by suggesting practical, real-world solutions wherever possible

5.3 Support people through individual experiences of health, illness and recovery.

For a GP who is proficient at supporting carers and families, this might involve:

- Recognising the benefits of continuity of care to the work of the professional (e.g. in getting to know about the situation of a family and understanding how ongoing illness or disability within that family affects other family members)
- Understanding that having a named health professional to liaise with can be immensely helpful for carers, as this reduces repetition, saves time for the carer and enables the carer to interact with the healthcare professional in the knowledge that he or she understands the situation that the carer is dealing with, even if the patient is not present
- Being alert to safeguarding issues and taking prompt and effective action when safety concerns are identified, using systems for raising concerns, finding support and whistleblowing when appropriate

5.4 Address the wider impact of ill health on the patient's life, work, family and community.

For a GP who is proficient at supporting carers and families, this might involve:

- For patients undertaking caring duties, identifying the impact of those duties on the carer's functioning, for example at school, at work, at home or in the community, and support the carer to maintain their level of functioning (for example, liaising with the carer's employer if time-out is needed for caring duties)
- Being alert to the presence of young carers under the age of 18 in families and providing support when a young carer is identified, considering that if carers are undertaking caring duties inappropriate to their age, this may be a safeguarding issue

5.5 Build relationships with the communities with which you work.

For a GP who is proficient at supporting carers and families, this might involve:

- Developing links with social and voluntary services locally so that you are aware of what they can offer to support carers and families and how those services can be accessed
- Developing links with local and national carer support organisations to enable them to provide advice and practical support within your own organisation

5.6 Encourage a holistic approach to care within the wider healthcare system.

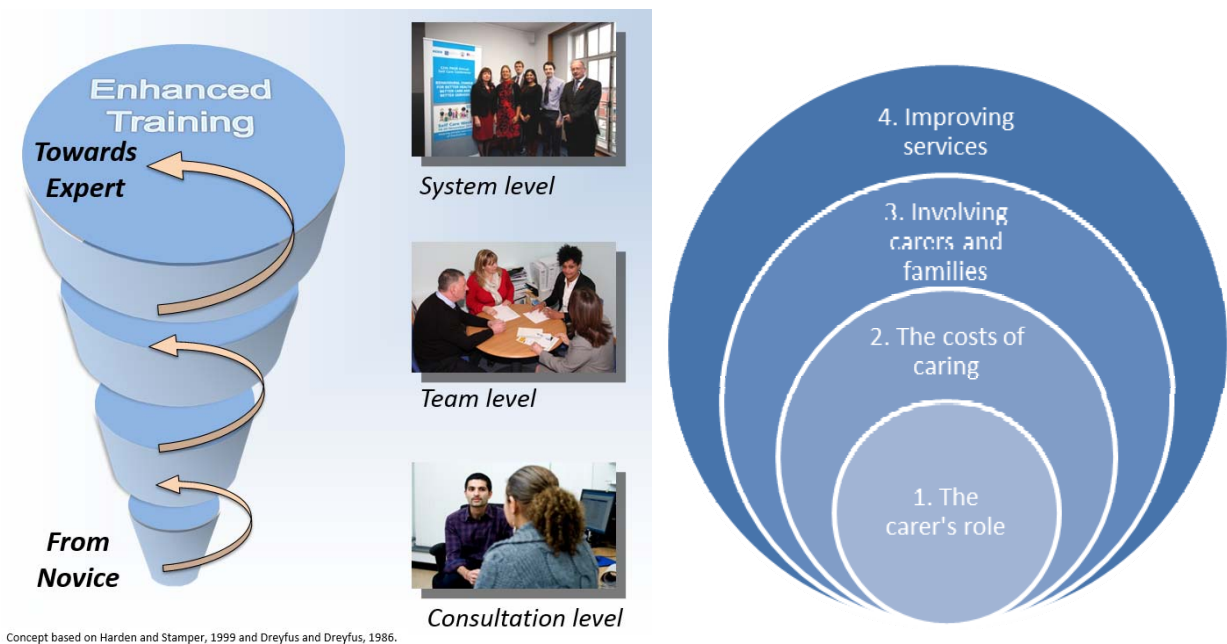
For a GP who is proficient at supporting carers and families, this might involve:

- Using holistic and shared decision-making approaches to co-develop treatment plans with patients and carers which incorporate an appropriate range of standard clinical and, where safe, effective and in keeping with patient preferences, complementary approaches to treatment
- Recognising the tensions created by the differing needs of the patient and carers, for example carers may neglect their own health for fear of jeopardising the care that they can provide for the people that they look after, and acting appropriately to manage these
- Recognising that resources available within health or social services may impact on the burden on carers and families, for example overstretched community nursing services may result in carers doing more nursing tasks for the people that they look after than they are either competent or confident to do
- Understanding the challenges and stress that carers and families face when trying to co-ordinate care and navigate the services and benefits available on behalf of a person that has a long term health condition

Approaches to learning

This section provides a practical approach to help GPs gain the knowledge and skills necessary to support carers within primary care. It is based on the spiral model being developed for enhanced GP training, starting with consideration of the individual carer, expanding to incorporate the role of multi-disciplinary teams, and ultimately encompassing services and the wider community of care (see Figure 1).

Figure 1: Spiral approach to learning how to involve and support carers and families.



1: The carer's role

GPs who have completed this section should be able to:

- Define the term 'carer' and 'young carer'
- Understand what carers do and the value that they have to society
- Acknowledge carers as partners in care, and
- Put in place strategies to identify carers in their local population.

Definitions

A carer is a person of any age, adult or child, who provides unpaid support to a partner, child, relative or friend who could not 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 misuse³.

Around half of all carers live with the person being cared for; but half do not. It is estimated that 12% of adults in the UK are currently carers¹ but this population is not static; 2 million people move in and out of caring roles every year and it is estimated that around 60% of people will be a carer at some point in their lives⁴. For every 10 carers, 3-4 will perform caregiving duties for over 20 hours each week, and 2 will perform caregiving duties for 50 hours per week or more⁵.

Young carers are children and young people under 18 who provide regular and ongoing care, and/or emotional support, to a family member who is physically or mentally ill, disabled or misuses substances. A young carer becomes vulnerable when the level of caregiving and responsibility to the person in need of care becomes excessive or inappropriate for that child, risking impacting on his or her emotional or physical well being or educational achievement and life chances⁶.

It is not entirely clear how many young carers there are in the UK as they are hard to identify. A 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 UK⁷. The true figure may be even higher, 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 years⁸. This implies that the true figure for the number of young carers in the UK may be nearer 1 million.

Suggested learning activities

- Consider completing an e-learning course (or similar) aimed at GPs to develop your baseline knowledge and to explore the roles and responsibilities of carers
- Review the patients that you have seen in you last clinic; could any of these patients have carers? If so, do you know who their carers are? Could any of the patients have been carers themselves?
- Identify a patient who has a carer. Ask permission to talk to the carer about what he or she does for the person being cared for and how the caregiving role has affected his or her life. Reflect how this has changed your view of the carer's role and document this in your e-portfolio
- Think of a patient who has an ongoing physical or mental health problem who lives in a family in which there are children. Consider if any of those children might be carers and what support they might need. Perhaps use this as the basis of a case-based discussion with your trainer.

What does a carer do?

People often gladly take on their roles as carers, but they do not usually choose to become carers. It is a role that may come suddenly and unexpectedly, for example after injury or sudden illness of another person, or may creep up over time, for example when looking after a relative or friend with a progressive illness.

Carers provide an extremely valuable service to the people that they look after. They enable many people who cannot look after themselves 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. It is estimated that carers save the UK economy in excess of £119 billion every year²; more than the entire health and social services budget combined and equivalent to £18,473 for every carer in the UK².

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 other carers would not be capable of
- Factors relating to the environment. For example, which services are available locally or whether the carer lives in the same home as the patient

Box 1 summarises the tasks that carers might do. In addition, many carers have to cope with abusive behaviour from the people that they care for. A survey of 1066 carers done by the Princess Royal Trust for Carers in 2002-3 (now the Carers Trust) found that 44% of the carers surveyed suffered verbal or emotional abuse and 28% suffered physical aggression or violence from the person that they cared for⁹.

Box 1: Common caring tasks

- Domestic tasks, such as shopping, cleaning, gardening, washing and/or ironing
- General care involving nursing tasks such as giving medication, changing dressings and helping with mobility
- Providing emotional support and supervision
- Intimate care, including washing the person cared for, dressing and attending to toileting needs
- Child care when parents are unable to care for children themselves
- Other tasks, such as bill paying, entertainment, accompanying to appointments and translating

Carers as partners in care

Carers know the people that they care for better than anyone else. This knowledge can be extremely useful to health and social care professionals in planning patient care, and also in identification of problems that may require intervention. If care is planned without the input of the carer, 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 the carer when devising a care plan, and listening to the carer's views, is likely to result in better concordance.

Suggested learning activities

- Consider the ethical problems, particularly regarding confidentiality, when involving carers in patient care for a) patients who retain capacity to make their own decision to share their medical information with carers and b) patients who lack capacity to make that decision
- Think of circumstances in which a patient might not be happy for confidential information to be shared with a carer. Reflect on how you might check and resolve this situation
- Pick a patient with an ongoing health problem who requires support from a carer:
 - Sit down with the patient and carer and identify the ongoing problems that they are experiencing
 - Discuss potential solutions with them, taking note of both the patient's and the carer's ideas, concerns and expectations
 - Negotiate a shared care plan that you, the carer and the patient can agree on and employ appropriate safety netting
 - Follow up to see how your plan has worked once implemented

Identification of carers

Without identifying carers, it is impossible for carers to be involved in patient care or to be supported. However, it is difficult to identify carers as anyone can potentially be a carer. Carers are also not a static population; people move in and out of caring roles according to their circumstances. Carers do not have any defining features that pick them 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 them¹.

Furthermore, many carers do not consider themselves as such. Caring is simply an extension of their usual role of spouse, partner, child, parent, friend or neighbour. In one survey 65% of people with a caring responsibility did not identify themselves as a carer in the first year of caring. For 32%, it took over 5 years before they recognised that they were carers¹⁰. These people are often referred to as 'hidden carers'. In the same study, around 50% felt that they had missed out on both financial and practical support as a result of remaining unidentified¹⁰.

Finally, some carers do not want to be labelled carers. They perceive that being branded a carer is not always beneficial. For example, it might hinder their job prospects or, for many younger carers, make them different from their peers.

Case study 1

Christine is 72 years old. She is retired. One day you are asked to do a home visit for Christine as she had fallen and broken her wrist the previous day. She has had the wrist manipulated and it is now in plaster, but she is in a lot of pain.

On arrival, you are surprised that a 7-year-old girl opens the door. She tells you that Christine fell over whilst collecting her from school. She is living with Christine as her mother is alcohol dependent and is currently undergoing a residential detoxification programme. Neither the child nor her mother (Christine's daughter) has ever been registered with your practice.

From what you can gather, the girl has been living largely with her grandmother for several years whilst her mother tries to sort out her alcohol problem. Even though Christine does everything that she can to support her daughter, she does not view herself as a carer – just a concerned mother. Before doing that home visit, you, as her GP, had absolutely no idea of Christine's caring role.

Case study 2

Nora is 90 years old and remarkably well for her age. She has never married and lives with her brother, Stan, who is 4 years younger than her. He has Alzheimer's disease and is slowly deteriorating. They have lived together all their lives.

One day Nora brings Stan to the surgery. At the suggestion that Nora is a carer, she bursts out laughing and says: *'Don't be daft; we've always looked after each other.'*

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

Young carers can be identified in the same ways as adult carers. 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 is carrying out inappropriate caring responsibilities. Some useful questions are listed in Box 2.

Box 2: Useful questions to ask families with potential young carers

- 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?
- If there is a child/young person in the family who helps to provide care, which tasks does he/she do?
- How does this affect the child/young person physically, emotionally or educationally?

Source: The Children's Society Include Project. Supporting young carers and their families: Information for healthcare professionals (2012).

Identification of carers is not the job of the GP alone. It should be a team activity in which the whole practice team is involved. Box 3 summarises some suggestions of ways to overcome the barriers to identification of carers in general practice.

Box 3: Possible ways to identify carers

- At registration
- Self-identification
- Opportunistically
- List searches
- At diagnosis or on hospital discharge
- Hospital admission
- When there is concern
- Via carer's organisations

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.

Suggested learning activities

- Around 12% of adults in the UK are carers; based on this figure, calculate how many carers you would expect to be registered with the practice that you are working in. How many carers are there on the practice carer register? Reflect upon why there is likely to be a discrepancy
- Look at the ways that carers are identified in the practice that you are working in. How might you improve carer identification? Consider discussing this with a colleague or at a practice meeting

2: The costs of caring

GPs who have completed this section should be able to:

- Describe the psychological effects of caring
- Describe the physical health problems associated with caring
- Describe the social effects of being a carer
- Describe the financial consequences of caring

Although carers do not generally choose to be carers, most would prefer to care for their loved ones themselves than have someone else care for them. Although many carers gain great personal satisfaction from their caring role and want to continue caring, there is evidence to suggest that they suffer health, social and financial consequences as a result. These are described separately here, however in reality health, social and financial effects of caring all impact upon each other. For example, financial hardship may result in restricted social activities; restriction of social networks may impact on psychological health; depression can cause self-neglect and thus physical health problems.

Psychological effects of caring

Carer surveys show that one-in-three carers providing care for over 50 hours a week reports depression, and one-in-two disturbed sleep¹¹. Such surveys have been criticised because they use self-selected populations of carers and self-reported health problems. However, independent research evidence supports these findings. A meta-analysis of 84 good quality studies has shown that up to 40% of carers have significant distress and depression levels, with behaviour problems causing the highest levels of distress^{12,13}. It is commonly thought that carer distress is a process of attrition. However, that is probably not the case. Information from the British Household Panel Survey showed that adverse effects on the psychological well-being of heavily involved carers were most pronounced around the start of caregiving episodes¹⁴.

For young carers, there may be conflict between the needs of the young carer and those of the person that the young carer is caring for. This may lead to feelings of guilt, anger, isolation (no-one else understands their experiences), or being trapped. Young carers may feel that there is nobody there for them, and that professionals do not listen or include them¹⁵. The pressures placed on young people through caring may result in behaviour problems, and in 2004, a study done in UK primary care reported that 'carer stress' from looking after a parent contributed to self-harm¹⁶. The Carers Trust confidential online support service for young carers has also found unexpectedly high levels of self-harm amongst the young carers that it supports¹⁷.

Suggested learning activities

- Consider doing an e-learning module (or similar) aimed at GPs about the problems that carers face
- Consider performing an audit to establish how many of those on the carer register have a diagnosis of depression; consider asking clinicians to screen carers opportunistically for depression and re-auditing 6 months later
- Consider auditing young people who have self-harmed; could any be young carers? If so, what help and support might you provide?

Physical health problems

In one postal survey 51% of carers reported physical injury as a result of caring; mainly back and shoulder injuries¹⁸. In the Princess Royal Trust Carer Health Survey, 61% of the 1066 carers who completed the survey reported currently feeling 'physically drained'⁹. In addition, 20% reported back injury as a result of caring (mainly amongst carers doing heavy physical caring for those with physical disabilities) and 10% put their high blood pressure down to the stress of caregiving. However, again these findings can be criticised because the populations surveyed were not necessarily representative of all carers, and the health problems were self-reported.

Research studies using more diverse populations of carers do support a negative effect of caring on physical health though, particularly in respect to cardiovascular disease. In one study, providing high levels of care was associated with a 23% higher risk of stroke¹⁹ and, in another, carers who reported 'strain' had a 63% higher likelihood of death in a 4 year period than non-carers or carers not reporting strain²⁰. Meta-analysis findings support a negative effect of caring on physical health but the effect is smaller than for psychological health. One meta-analysis of 23 studies compared the physical health of carers looking after people with a diagnosis of dementia with demographically similar non-carers²¹. When examined across 11 health categories, carers exhibited a slightly greater risk for health problems than did non-carers. Another meta-analysis of 84 studies comparing carers looking after people with a variety of problems with non-carers concluded that differences in the levels of physical health in favour of non-carers were statistically significant, but small¹³.

Suggested learning activities

- Use a case-based discussion to compare and contrast carers that you come into contact with as a result of your work; what health problems do they have and how might these problems be related to their caregiving roles? Could anything be done to prevent these health problems?
- Consider performing a significant event analysis if a patient is admitted to hospital because of a health problem affecting the carer. Is there any way that admission could have been avoided?
- Consider performing a significant event analysis if a patient is admitted to long-term residential care because the carer is no longer able to cope. Could anything have been done to support the carer better?
- Discuss with your trainer or peers why carers may neglect their own health and suggest and implement ways in which access to healthcare could be made easier for carers

The social effects of caring

Case study 3

Doug is 44 years old. Until last year he was employed full time working for an electronics company. He is married with two children aged 9 and 7 and owns his own home. Ten months ago, his wife, Sharon, was involved in a road accident. She sustained a severe head injury and although now home, she has been left severely disabled, needing 24-hour care.

Doug comes to see you at the surgery one day. In passing, you ask Doug how he is coping at home and he admits that he is finding life tough. Although he wants to look after Sharon, he is struggling. At first there were lots of people who would come round to help him but now he feels alone. He is missing the social contact that he had with his work mates, and also his regular games of squash in the local squash league. He feels he no longer has anything in common with his peers and his old friends are drifting away. His financial situation is perilous and his mortgage is in arrears. To add to everything, his 9-year-old son is 'playing up' at school.

Caring can impact on all dimensions of family functioning and wellbeing. Many carers emphasise positive reasons for caring and the benefits that they receive. However, carers also report adverse effects of caring on social functioning, including activity restriction, 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 carers²².

Young carers may have difficulties playing 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 both at home and at school. 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 report²³. Many carers continue to have emotional problems into adulthood as a result of caring and may have ongoing difficulties establishing relationships.

Suggested learning activities

- Consider spending a session with your organisation's carers lead to find out what his/her role entails and what is available in your organisation to support carers
- Explore the availability of carer support organisations in your locality both for adult and young carers; consider visiting these organisations to find out what they do and which services they provide
- Put together a carer information pack (or modify and update the existing pack) for the organisation in which you are working

Effects on education and employment

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 group²³ and include:

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

Caring can also affect ability to work and job prospects. One-in-five carers gives up work to care, and on average carers retire 8 years early. In households of working-age carers looking after their partners, no-one in the household is in paid work in 87% of cases²⁴. However the effects of caring can also be more subtle, for example by hindering promotion prospects.

Suggested learning activities

- Find out who supports young carers in local schools around where you are working; consider meeting with one of these carer leads and finding out how young carers are supported within school
- Find out what the carer policy is for employees within the organisation for which you work; if there is no policy, consider working with the practice manager to develop one

Financial cost of caring

Perhaps unsurprisingly, 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. Many carers' financial situation is so difficult that they are struggling to pay even basic bills. In one Carers UK survey, 52% had cut back on buying food, 65% of carers were in fuel poverty and 74% had difficulty paying essential utility bills. Over half (55%) were also in debt as a result of their caring responsibilities²⁵. Financial problems appear to be 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.

However, information from the Princess Royal Trust Carers Centres suggests that fewer than 50% of carers claim all the benefits that they are eligible for. This finding is supported by data from Carers UK. They found that 81% of respondents to their survey 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 support¹⁰. Half felt that they had missed out on benefits.

Case study 4

Nisha is 20 years old. Both Nisha and her mother, Nusrat, are registered at your surgery. Nusrat had an operation to remove a spinal tumour when Nisha was 14. This left her with a severe spinal cord injury and paraplegia. She subsequently also developed severe depression after Nisha's father left. Nisha comes to see you one day with her mother as part of Nusrat's long overdue medication review.

During the course of this review, you ask Nisha how she is and she bursts into tears; she is struggling. Living with Mum has been very difficult. She was unable to complete her studies due to her caring role and left school at 16 with only a couple of GCSEs. She is now Nusrat's fulltime carer. She is socially isolated and apart from their Universal Credit and Nusrat's Personal Independence Payments, they have no other income as neither Nisha nor Nusrat is able to work. They are struggling to make ends meet. She admits tearfully to feeling trapped and asks you for help.

Suggested learning activities

- Contact your local carers organisation or Citizen's Advice Bureau to find out what benefits might be available to support carers and how these can be accessed; consider making a leaflet for carers about benefits that might be available and including it in your organisation's carer information pack or putting it on the website
- Contact social services and find out about Carer's Assessments, who is eligible and what they cover; consider auditing what proportion of carers on your carers register have been referred for social services Carers Assessment
- Consider writing a short piece for your practice newsletter about support available for carers both within your organisation and more widely in the local community

3: Involving carers and families

GPs who have completed this section should be able to:

- Involve carers in patient care as team members, understanding the issues surrounding confidentiality that may inhibit sharing of information with carers
- Deliver high quality healthcare for carers, taking into consideration the barriers to healthcare that they face
- Provide and signpost carers to sources of information and training to support them in their roles
- Understand the roles of other members of the multidisciplinary team and other services in the support of carers and work effectively with them to provide joined-up, holistic care

Involving carers and families in patient care

Earlier in this document, we described how carers often know the people that they care for better than anyone else and that this knowledge can be extremely useful in planning patient care, and also in identification of problems that may require intervention. 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, and so involving the carer when devising a care plan, and listening to his or her views, is likely to result in better concordance.

However, many carers and family members feel that they are not recognised as partners in care. There are several reasons for this. For example, the carer may not be present when decisions are made. This commonly occurs if the patient and carer are not co-resident, but may also occur if decisions are made at multidisciplinary team meetings at which a number of patients are discussed and thus individual carers cannot be present. Another commonly cited worry is that of confidentiality.

Professionals have a duty to respect the confidentiality of their patients and this can leave doctors anxious about talking to carers. This in turn can make involving carers as part of the multidisciplinary team caring for the patient difficult. Finding ways to share information can make a critical difference to the ability and confidence of a carer to perform a caring role, and the information and support that the multidisciplinary team can gain from the carer.

It is important to talk to patients routinely about issues surrounding information-sharing. Actively seek permission (written and signed by the patient where possible) for carers to be given information about patient care and treatment. Record this in the patient's notes so that everyone is aware that permission to share information has been given. In some areas, carer centres have supplies of preformatted consent forms to be signed by the patient and carer and registered by the practice.

Where patients are reluctant for all information to be shared, ask if there are aspects of their conditions 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 carers.

Mental capacity

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), in order to demonstrate decision-making capacity *all four* of the following criteria must be met. A person should be able to:

- Understand the information relevant to the 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 the patient's *best interests* should be acted upon²⁶.

Consider the views of family and friends where practicable. 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. In most cases, it is in the patient's best interests to share information with the patient's carer.

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 patient 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.

Case study 5

Linda is 64 and has terminal breast cancer. She is losing weight and becoming more and more reliant on her partner, Max. They have been together for five years and Max is very supportive and clearly cares for Linda. During a routine review, you ask Linda if you can share her medical information with Max but she refuses.

How might you approach this situation?

It is important to establish the reasons why Linda does not want to share her medical information with Max. In this case, you have a frank discussion with Linda about the benefits of sharing medical information with Max to enhance her care. Linda responds that she understands the reasons for sharing her information and would like Max to be involved as much as possible in her care. However, Linda has not told Max about a string of overdoses that she took when she was in an abusive relationship in her twenties. She feels very embarrassed about these episodes and does not want Max or her children to know about them.

She welcomes the suggestion that it would be possible to share information with Max about her cancer and the care that she needs currently, without allowing him access to any information about her past medical history. Written and signed confirmation is supplied by Linda, and a notice put on her electronic record to this effect.

Suggested learning activities

- Find out if the organisation that you are working for has a standard consent form to enable staff to share patient information with carers; if not consider devising one with the assistance of your local carers organisation
- Consider performing an audit of patients who are recorded as having a carer; what proportion have written and signed consent in place to share confidential medical information with their carers? How might this be improved?
- Consider using a situation in which you have involved a carer in patient care as the topic of a case-based discussion or mini-CEX with your trainer

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. However, sometimes the reason is more subtle. For example, carers may not attend to their own health problems as they are worried that they might be prevented from continuing to care if a major health problem arose.

Whenever you see a carer with a patient, it is always worth enquiring about the well-being of the carer. 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.

Remember that around 40% of carers suffer from significant psychological distress. Consider using a tool such as the National Institute for Health and Care Excellence (NICE) depression screening questions to screen for depression at least once a year²⁷. A positive response to one or both of the screening questions should trigger further exploration of the carer's mood, for example using the PHQ-9 questionnaire.

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 carers 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. In some cases it is routinely necessary to make double appointments for carers to enable this.

For carers looking after the most dependent individuals 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 cannot get out to come to an appointment but requires medical care.

All carers are entitled to a free annual influenza vaccination on the NHS, so carers should be invited to attend for vaccination in the same way as those from high health-risk groups. For patients being vaccinated at home by the community nursing services, asking if the carers can be vaccinated at the same time may save the carers and the practice time. Putting a notice up in the practice inviting carers to attend for influenza vaccination and also in the letters inviting patients from priority groups for vaccination may also reveal new carers that you were unaware of previously.

Some practices offer additional services for carers. Examples include annual health checks for carers with the practice nurse, 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.

Case study 6

Hilda and Stan are a delightful couple in their 80s. Hilda has cared for Stan since he had a stroke 15 years ago which left him slow with his walking and with impaired speech. She has been offered respite care but had a bad experience several years ago and will not allow Stan to go into respite care again. Hilda comes to see you every 3-4 months for you to give a steroid injection into both her knees. Her X-ray shows severe osteoarthritis but even though the injections are having less and less effect she resolutely refuses to consider the possibility of knee replacement surgery because she would have to relinquish her caring responsibilities whilst she recovered.

Suggested learning activities

- Ask if the organisation that you are working in makes any special allowances or provision for carers when booking appointments. If so, reflect upon how this system could be improved. If not, discuss this issue at a practice meeting with a view to creating a policy to make appointments to address carers own healthcare needs easier to access
- Consider performing an audit of the proportion of carers on the carers register who have received flu vaccinations. Examine the letters inviting patients for annual flu vaccinations. Are carers automatically invited? Could letters, web-based information and posters be amended to include an invitation for carers to identify themselves and receive vaccination too?
- Consider a case in which a patient that you have seen has refused treatment because of caring responsibilities as a topic for a case-based discussion with your trainer

Information, training and support

The role of the GP and primary care team in provision of information, training and support to carers 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.

Carer centres and other services for carers provided by local and national carers' charities are a very valuable source of help and support. In addition to information provided by carers' charities, the Department of Health's NHS website 'Carers Direct' provides information and educational resources for carers and health professionals about carers' issues. The Gov.uk website 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 and through its local offices.

Disease-specific organisations (such as the Stroke Association, Macmillan Cancer Support, Age UK, Parkinson's Disease Society, Contact a Family, the Alzheimer's Society and MIND) also provide excellent disease-specific information, and more general support, for both patients and carers.

Carer training can also be valuable. Carers Direct runs online self-study learning programmes to help carers in their caring role. The programmes aim to help carers to understand:

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

Self-study workbooks mirroring the on-line learning programme are also available to download from the Carers Direct website for those who do not want (or are unable) to do the modules on-line. Some carer organisations provide group learning sessions covering the same material, and the Expert Patient scheme also runs courses for carers. Currently two courses are available: 'Caring with Confidence' and 'Looking after me'.

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. Manual handling courses may benefit carers who have to do a lot of heavy lifting and prevent musculoskeletal injuries.

Medication is another issue of concern for many 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 boxes (such as Nomad trays).

Suggested learning activities

- Compile a list of both national and local sources of information and support for carers. Discuss within your organisation how this list could be made easily accessible to both carers and also healthcare professionals who may wish to signpost carers to these resources
- Refer a carer for support from a local carers organisation and follow up what happens (if a formal assessment is done, the carer's organisation may allow you to sit in on their consultation with the carer); use this as a topic for a case based discussion with your trainer
- Consider doing a web-based carer training module aimed at carers and/or watching the RCGP Supporting Carers in Primary Care DVD and reflect on the content of these resources
- Consider auditing carer support within the organisation that you are working in using a standardised audit tool such as the RCGP Self-Assessment Checklist
- Consider performing a carer survey and/or organising a carers focus group to obtain 'users' views' about the service provided by the organisation that you are working within and suggestions for improvements that could be implemented

Providing holistic, joined-up care

Experience shows that in primary care it can be easier to make improvements for carers with someone to champion their cause within a GP practice¹⁷. 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.

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. Box 4 suggests some roles that could be taken on by a carers' lead.

Box 4: 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 updated with developments in carer support at a local and national level
- Audit practice activity to support carers e.g. using the self-assessment checklist produced by the RCGP and 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.

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. There is no definition of what constitutes a regular and substantial amount of care. 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 re-assessment.

A systematic review assessing the efficacy of interventions to support carers²⁸ suggests that statutory Carer Assessments can be very helpful to carers. Assessments can be of practical benefit through providing carers with links to other direct support services but this only occurs for a proportion of carers (less than 50%). However, carers also find assessment to be a useful cathartic process as it allows them to express themselves, reflect upon their situation, receive recognition and validation from others and feel supported.

Emergency planning should be part of the local authority Carer's Assessment. Legislation means that carers should 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.

Suggested learning activities

- Consider doing the RCGP e-learning module on the topic of organising your practice to support carers
- Explore the possibility of inviting a carer to come to speak to your practice or vocational training scheme about his or her own personal experiences of being a carer and the challenges of navigating the health and social care system
- Find out how to refer carers in your area for a social services Carer's Assessment; Discuss at a practice meeting how referral for Assessment could be made easier (e.g. using a standardised electronic referral form)
- Consider auditing the proportion of people who are on your carers register who have an emergency care plan in place

4. Improving services for carers

GPs who have completed this section should be able to:

- Map services currently available and explore service use data
- Discover through consultation with service users and gap analysis where services need to improve or change
- Explore the options to deliver change
- Get involved with progress to achieve change

Mapping current services

Before improving services or developing new services it is important to establish:

- What is already available
- Who provides existing services and how they are funded
- How frequently services are used and by whom

This is a process known as asset mapping²⁹. Support for families and carers is provided via a vast array of different sources. For example, carers receive health care through the NHS - often both in primary and secondary care settings. They may receive input via the local social services department, for example by provision of Carers' Assessments or emergency care plans. Voluntary sector organisations may provide information and support, or even respite or nursing services. Commercial organisations may provide respite, home care or other services such as podiatry. Schools support young carers and other school-age family members. Employers may support workers who have caring responsibilities, and even the internet has a role in providing information and support (such as chat rooms, or social media sites where carers can share experiences).

One of the major problems surrounding carer support is that the organisations involved are very diverse, vary considerably from location to location, change frequently, and funding may come via the health, social services, third sector (encompassing most charity organisations), commercial sector or a combination of sources. Although carer organisations are usually experts about what is available locally, it can be quite a challenge to map those assets accurately.

Once the assets have been mapped, if you are proposing to improve or change service provision, it is important to know the size of the task that you are dealing with. The resources needed for an organisation that has 10-15 carer contacts a month will be very different from those receiving 2000-3000 carer contacts per month. Service use data may be available from a number of sources. For example, NHS and social services departments have service use data collected routinely and this should be freely available.

It is also important to know how services are funded. Most organisations that support carers and families can readily identify areas of their work that they would like to improve or in which they would like to expand their services. However, they are often limited by the resources available. As well as understanding existing funding streams, it is useful to know what resources (both financial and in terms of buildings and personnel) it would take to extend capacity and capability.

Suggested learning activities

- Interview the carer of a patient that you see regularly about the services that he or she uses. Create a map of the services accessed by that one user and try to find out how each service is funded. Reflect whether there are any gaps in service provision for this carer and try to find out whether there are any local resources already available that might be able to fill that gap.
- Find out how Direct Payments work and reflect with your trainer about the pros and cons of this system and how Direct Payments might influence provision of services
- Meet with your local carer support organisation and find out how they are funded and how many carer contacts they have each year; ask about the services their organisation provides, their ideas for improvement or expansion of services and the barriers to achieving those changes; ask about other local services and try to find out which they think are particularly effective, and if there are any gaps in services that they would like to see filled.

Consultation with service users

It is impossible to know what any group of service users would like without asking them. There are many different ways in which this can be done, and an approach using a variety of different methods designed to reach the widest possible range of potential service users is ideal.

A useful first step is to look at published data. For example, research studies involving carers give an insight about what carers want generally. National carer support organisations frequently do carer surveys and information from these surveys is also very useful. Tapping into the views of current service users can be extremely helpful too. For example, surveying carers registered with your practice about access, inclusion in care planning and support can be a useful way of identifying ways to improve the service already being offered. When performing surveys, it is important to obtain as high a response rate as possible in order to obtain a wide spread of views. High response rates can be achieved by asking carers to complete survey forms whilst on the premises, using telephone interviews to obtain carer views and by actively chasing up non-responders to postal surveys.

Other useful sources of information about local services that work well and those that do not, are local peer support groups. These might be carer support groups, but could also be support groups for sufferers of long-term conditions who commonly have carers, such as dementia support groups, or local branches of MIND. Expertise of the carers attending these groups can be tapped through traditional surveys, but often focus groups are more effective.

However, when engaging with carers to explore service provision, it is also important to access those carers who are harder to reach. For example, carers who work full time have problems that are unique to them, and are unlikely to go to the GP surgery very often, or attend community support groups. Other hard to reach carer groups include young carers, young adult carers, those from minority ethnic groups, and those from the gay community. Engagement with 'hidden' or 'hard-to-access' carers is vital to understand how to improve access for them.

Suggested learning activities

- Look up recent survey data from national carer support organisations such as Carers Trust and Care UK and do a research literature review for a particular group of carers (for example, carers of people with severe mental illness or substance misuse) to find out what sort of support might be needed by carers of those patients and what works; consider presenting your findings to your local vocational training scheme or peer group
- Consider performing a survey of carers' views of access, inclusion in patient care and carer support provided by your own organisation; present this at a practice meeting and discuss ways of addressing any problems identified by the survey with the whole practice team
- Consider going to a meeting of a local carer or condition-specific support group and talking to a focus group of carers about local services. In particular, find out:
 - Which local services the group appreciates and why
 - Which local services the groups thinks could be improved and what they would like to see changed, and
 - Whether there are any additional services that the groups would like to see that are not currently available in the area
- Reflect on reasons why carers might be hard to access and think of as many ways as you can that might enable you to access the views of 'hard-to-reach' or 'hidden' carers
- Consider reporting your findings to your local CCG or Primary Care Organisation

Exploring the options to deliver change

Based on a review of all the available information, from carers themselves, existing service providers, and the carer literature, you may have a clear idea of a service improvement that would benefit local carers.

The next step is to explore the ways in which the need that you have identified could be addressed and the resource implications for each model that you devise. So, for example if you identify there is a need for GPs to be able to refer carers to the local carer's centre for help with benefits and accessing support in the community, then you would need to find out:

- 1 Which local carers centres operate within the area that you would like this scheme to cover (you may find that these centres are run by several different providers)
- 2 Do any of these carer centres already operate a similar scheme that could be expanded?
- 3 Would all the carer centres want to participate in the scheme?
- 4 How many referrals would you expect to have to deal with in any year?
- 5 How would these be distributed across the region and the participating carer centres?
- 6 What are the resource implications for the carer centres that would participate (financial, personnel, space)?
- 7 What are the resource implications for the GP practices involved?
- 8 How would the scheme be co-ordinated?
- 9 How would the scheme actually work?
- 10 Would the scheme be cost-effective?

Case study 7

In 24 GP practices in Cambridgeshire, GPs issue carers with a free prescription to contact Crossroads Care Cambridgeshire (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 (now Carers Trust) 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 commissioners and is available for carers of any age. GP commissioning groups have supported expansion of the service to all 77 practices in Cambridgeshire.

Source: RCGP Commissioning for Carers (2013). Accessed via: <http://www.rcgp.org.uk/clinical-and-research/clinical-resources/~media/Files/CIRC/Carers/RCGP-Commissioning-for-Carers-2013.ashx>

Suggested learning activities

- Contact your local Primary Care Organisation and find out about their carers policy and who is the carer lead responsible for overseeing services to support carers; what initiatives to support carers are currently in progress in your locality? Consider attending a meeting with the carers lead at which these issues will be discussed and reflect on your experience with your trainer
- If work that you have done with carers (for example, a carers survey in your practice or a focus groups with a local service group), has suggested a gap in local service provision for carers or any area of service provision that could be improved:
 - Think of possible ways that you could address the issue identified, being innovative but also taking into consideration existing resources, and considering the resource implications that any change might have
 - Consider bringing the issue to the attention of the locality carers lead and finding out what steps you might take to take your ideas further

Getting involved to achieve change

Services for carers may be commissioned at a number of levels (figure 2). Commissioning processes vary in the different nation-states of the UK, and it is important to know how the commissioning process works in your area and who is responsible for commissioning.

Figure 2: Levels at which commissioning of services to support carers might occur

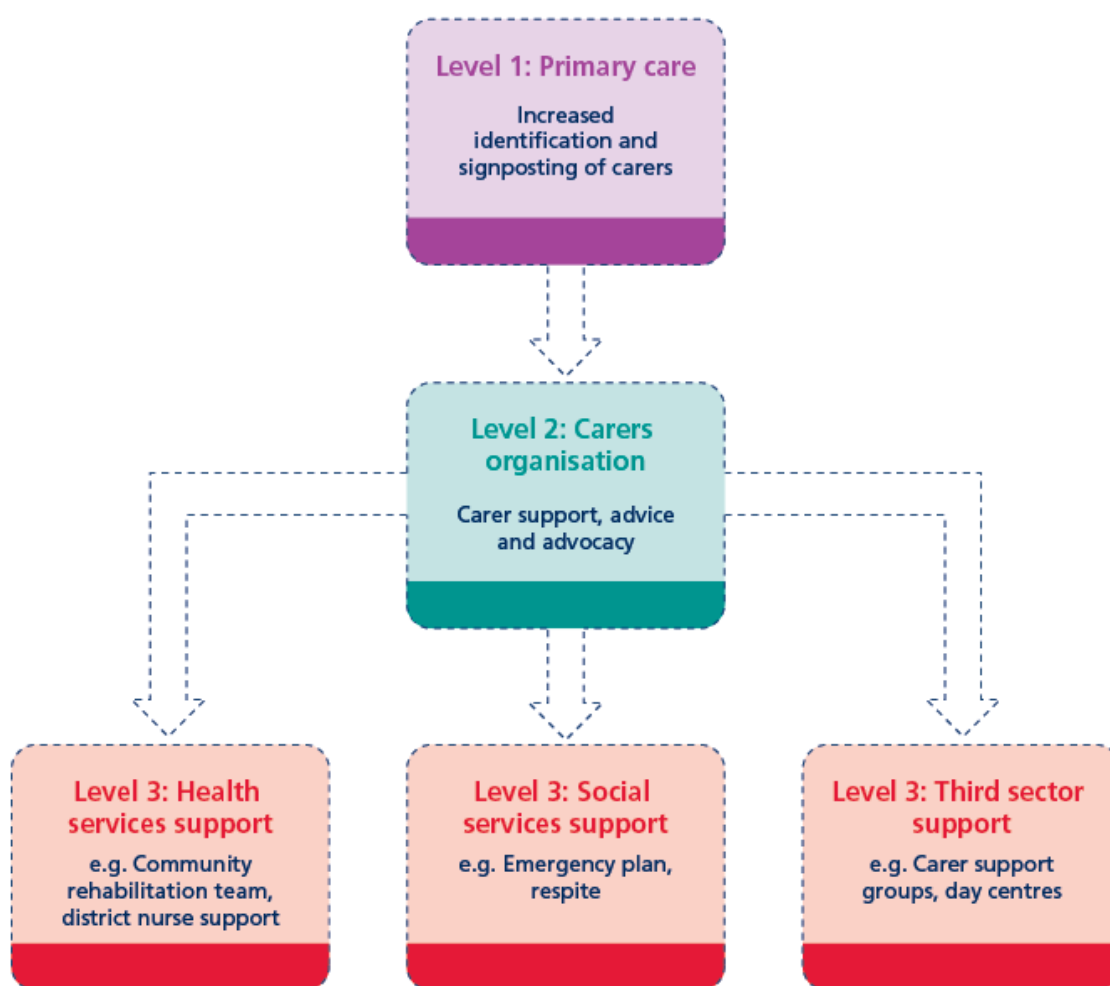


Figure 2 is reproduced from RCGP Commissioning for Carers (2013). Accessed via: <http://www.rcgp.org.uk/clinical-and-research/clinical-resources/~media/Files/CIRC/Carers/RCGP-Commissioning-for-Carers-2013.ashx>

Models of carer support

Furthermore, in different areas of the UK there are different models of carer support. Broadly these fall into two categories: the umbrella approach and the integrated approach (Figure 3).

Figure 3: Design of locality provision for carers

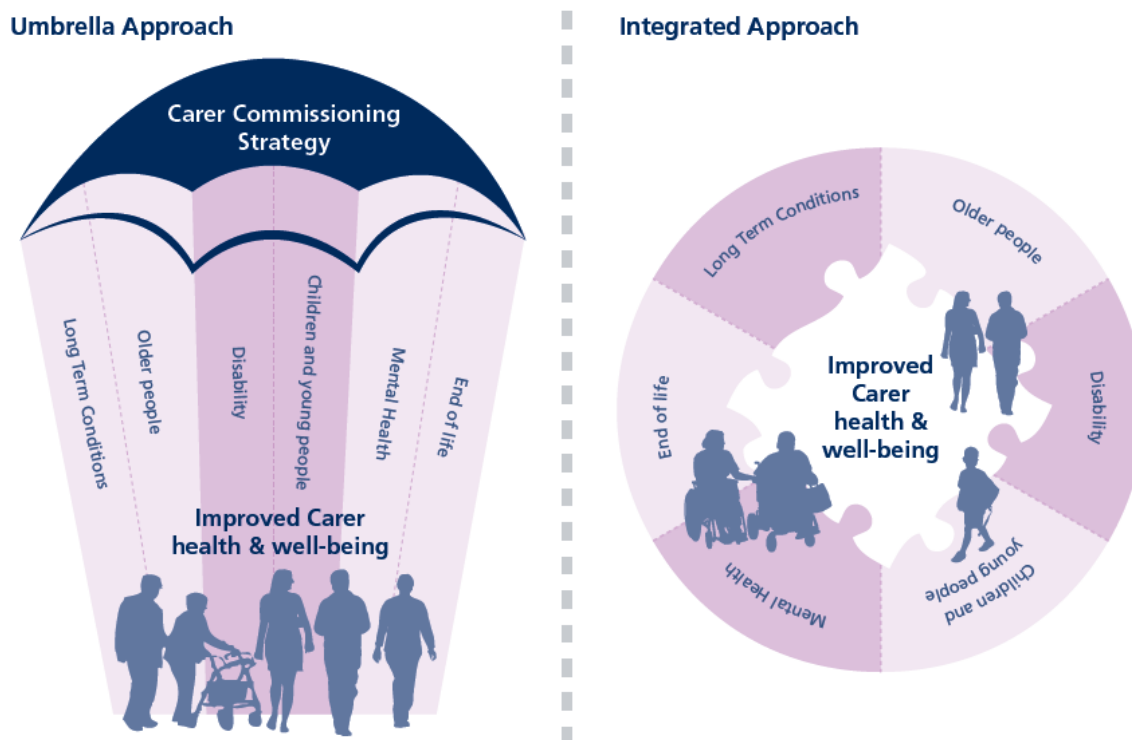


Figure 1 is reproduced from RCGP Commissioning for Carers (2013). Accessed via: <http://www.rcgp.org.uk/clinical-and-research/clinical-resources/~media/Files/CIRC/Carers/RCGP-Commissioning-for-Carers-2013.ashx>

It is important to understand the model being used locally. Under the umbrella approach there is an overarching carers' strategy applied within the locality across all public services that addresses the needs of all carers and is separate from other commissioning programmes. Therefore change can be achieved for all carers through a single channel. The integrated approach addresses carers' needs as a part of each individual programme to commission services. So for example, when commissioning services for long-term conditions, the primary care organisation and/or local authority is required to consider the needs of carers in that programme. To achieve change for all carers, a number of different programmes will need to be involved.

Suggested learning activities

- Find out who is responsible for commissioning carer support services in your area and how the commissioning process works
- Consider spending a day with a team responsible for contracts at your local primary care organisation and find out how commissioned contracts are monitored and enforced
- Find out how the policy for carer support works in your area; is an umbrella or an integrated approach in operation? Discuss the pros and cons of each with your trainer
- Consider using your Quality Improvement Project to improve carer support in your area

Useful learning resources

1. RCGP/Carers Trust. Supporting carers: An action guide for General Practitioners and their teams (2011). Accessed via: www.rcgp.org.uk/clinical-and-research/clinical-resources/~media/Files/CIRC/Carers/Carers-Action-Guide.ashx
2. RCGP. Supporting carers in general practice DVD (2012).
3. RCGP e-learning/e-GP. 4 sessions on supporting carers in primary care
4. RCGP. Commissioning for Carers (2013). Accessed via: www.rcgp.org.uk/clinical-and-research/clinical-resources/~media/Files/CIRC/Carers/RCGP-Commissioning-for-Carers-2013.ashx
5. RCGP InnovAiT, Special issue: Carers. (2011 4 (8)
6. Carers Direct: Understanding carers. Accessed via: www.nhs.uk/carersdirect/understanding-carers/pages/understanding-carers-home.aspx
7. Carers Direct: On-line learning. Accessed via: www.nhs.uk/CarersDirect/carers-learning-online/Pages/carers-online-learning.aspx
8. Department of Health. National Carers Strategy: Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own (2008 with 2010 update). Accessed via: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085345
9. Department of Health. 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
10. Royal College of Psychiatrists. Carers and confidentiality in mental health (2010). Accessed via: www.rcpsych.ac.uk/about/campaigns/partnersincarecampaign/carersandconfidentiality.aspx
11. Frank J. Making it Work. Good practice with young carers and their families (2002) The Children's Society with The Princess Royal Trust for Carers. Accessed via: www.youngcarer.com/pdfs/MAKING%20IT%20WORK%20Vol%201.pdf
12. The Children's Society Include Project. Supporting young carers and their families: Information for healthcare professionals (2012). Accessed via: www.youngcarer.com/sites/default/files/imce_user_files/Resources/Professional/Booklets/health_care_pros_booklet_2012_low_res.pdf
13. The Children's Society. A quick checklist for supporting and signposting young carers (2012). Accessed via: www.youngcarer.com/sites/default/files/imce_user_files/Resources/Professional/Booklets/quick_checklist_feb_2012.pdf
14. The Children's Society/Carers Trust/Disabled Parents Network. The whole family pathway: A resource for practitioners (2008). Accessed via: www.youngcarer.com/pdfs/Whole%20Family%20Pathway%2010th.pdf
15. GMC. 0-18 years: Guidance for all doctors (2007). Accessed via: www.gmc-uk.org/static/documents/content/0-18_0510.pdf
16. GMC. Confidentiality (2009). Accessed via: www.gmc-uk.org/static/documents/content/Confidentiality_0513_Revised.pdf
17. Office of the Public Guardian. The Mental Capacity Act: Making decisions – a guide for people who work in health and social care (2009). Accessed via: www.publicguardian.gov.uk/docs/opg-603-0409.pdf

References

1. NHS Information Centre for Health and Social Care. Survey of carers in households 2009/2010 (2010). Accessed via:
www.ic.nhs.uk/webfiles/publications/009_Social_Care/carerssurvey0910/Survey_of_Carers_in_Households_2009_10_England.pdf
2. 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
3. RCGP/Carers Trust. Supporting carers: An action guide for General Practitioners and their teams (2011). Accessed via: www.rcgp.org.uk/clinical-and-research/clinical-resources/~media/Files/CIRC/Carers/Carers-Action-Guide.ashx
4. Carers UK. It could be you, the chances of becoming a carer (2001) Accessed via: www.carersuk.org/Professionals/ResearchLibrary/Profileofcaring/1207223744
5. UK census (2001)
6. Department of Health. 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
7. 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
8. 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
9. The Princess Royal Trust for Carers. Carers Health Survey (2004) Accessed via:
<http://static.carers.org/files/carershealthsurvey-12.pdf>
10. Carers UK. In the know (2006) Accessed via:
www.carersuk.org/Professionals/ResearchLibrary/Profileofcaring/1201108799
11. National Statistics. Health symptoms felt by informal carers: by number of hours spent caring, 2000/01. (2003). Accessed via:
www.statistics.gov.uk/STATBASE/ssdataset.asp?vlnk=6496
12. Pinquart M, Sorensen S. Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: a meta-analysis. *Journal of Gerontology Series B Psychological Sciences* (2003a) 58(2), pp. P112-P128.
13. Pinquart M, Sorensen S. Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychology and Aging* (2003b) 18 (2), pp. 250-267.
14. Hirst M. Carer distress: a prospective population based study. *Social Science & Medicine* (2005) 61 (3), pp. 697-708.
15. Frank J. Making it Work. Good practice with young carers and their families (2002) The Children's Society with The Princess Royal Trust for Carers. Accessed via:
www.youngcarer.com/pdfs/MAKING%20IT%20WORK%20Vol%201.pdf
16. Poustie A, Neville R. Deliberate self harm cases: a primary care perspective. *Nursing Standard* (2004) 18 (48): 33-36.

17. RCGP/Carers Trust. Supporting carers: An action guide for General Practitioners and their teams (2011). Accessed via: www.rcgp.org.uk/clinical-and-research/clinical-resources/~media/Files/CIRC/Carers/Carers-Action-Guide.ashx
18. Henwood M. Ignored and Invisible? Carers experience of the NHS (1998) Carers National Association.
19. 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.
20. Schulz R, Beach S. Caregiving as a risk factor for mortality. *Journal of the American Medical Association* (1999) 282 (23): pp. 2215-2219.
21. Vitaliano PP, Zhang J, Scanlan JM. Is caregiving hazardous to one's physical health? A meta-analysis (2003) *Psychological Bulletin* 129 (6) pp. 946-972.
22. 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
23. 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
24. Carers UK. Real change not short change: Time to deliver for carers (2007) Accessed via: www.carersuk.org/Professionals/ResearchLibrary/Financialimpactofcaring/1201109152
25. Carers UK. Carers in Crisis (2008) Accessed via: www.carersuk.org/Professionals/ResearchLibrary/Financialimpactofcaring
26. Office of the Public Guardian. The Mental Capacity Act: Making decisions – a guide for people who work in health and social care (2009). Accessed via: www.publicguardian.gov.uk/docs/opg-603-0409.pdf
27. 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>
28. Victor E. A Systematic Review of Interventions for Carers in the UK: Outcomes and Explanatory Evidence (2009). Accessed via: <http://static.carers.org/files/systematic-review-15-jan-3840.pdf>
29. RCGP. Commissioning for Carers (2013). Accessed via: www.rcgp.org.uk/clinical-and-research/clinical-resources/~media/Files/CIRC/Carers/RCGP-Commissioning-for-Carers-2013.ashx