



The Princess Royal Trust  
*for Carers*

directors of  
**adass**  
adult social services

## SUPPORTING CARERS – EARLY INTERVENTIONS AND BETTER OUTCOMES



May 2010

**Photographs:** Princess Royal Trust for Carers, photo library.

### **Definition of Carer**

There is currently no single agreed definition of what is meant by the term “carer”. The National Strategy for Carers<sup>1</sup> in 2008 included a draft cross government definition for consultation. Within this paper we have used the definition contained within *Commissioning for Carers* [2009]<sup>2</sup> developed jointly by a number of carers and commissioners’ organisations including the Association of Directors of Adult Social Services [ADASS] and The Improvement and Development Agency [IDeA]:

*A carer spends a significant proportion of their time providing unpaid support to a family member, partner of friend who is ill, frail, disabled or has mental health or substance misuse problems.*

### **Focus of this Paper**

The focus of this paper is on the care and support of adults, particularly older people, by adult carers. The paper does not seek to consider the position of young carers or carers of children with disabilities.

### **Please Note**

This review paper is intended to be a contribution to debate. Whilst every attempt has been made to ensure accuracy and promote best practice we cannot accept any responsibility for loss or liability occasioned as a result of people acting or not acting on information contained in this paper. Reference should be made to full copies of the relevant documents as appropriate. Further information or legal advice is sought as necessary.

Should any conflict or apparent difference in interpretation arise in relation to current statutory or accepted best practice guidance, the expectation is that the statutory and best practice guidance would take precedence. It should also be remembered that practice guidance along with research is developing all the time and should inform local decision making and action having regard to local needs and circumstances.

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## FOREWORD



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Over the last two years we have been working together to take forward the National Carers' Strategy, published in 2008, in the context of more personalised support and sustained independence for carers and service users. This paper is the third in a sequence of short reviews designed to stimulate debate and improve the support for carers.

At a time when we face many challenges around resources it is doubly important that we keep our sights firmly on the improved outcomes that can be secured through early intervention and preventative support.

The review contains five key messages. They support the current policy advice on personalisation and eligibility for support. They highlight the good evidence that does exist, but also point to a need for a much stronger evidence base around which service users, carers, commissioners and providers can better judge how well we are doing.

These aspects are all relevant to achievement of the aims of the national strategy for carers that we have signed up to. In summary, a stronger focus on better outcomes and value and the ability to evidence this through innovation, partnership with carers and by taking the opportunities locally to secure a strategic shift towards prevention and early intervention is needed.

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**Alex Fox**

Handwritten signature of Graeme Betts in black ink.

**Graeme Betts**

## 1 - KEY MESSAGES

Department of Health guidance<sup>3</sup> [2010] on whole system approaches to prioritising need in the context of *Putting People First*<sup>4</sup> states:

10. To effectively deliver the transformation envisaged in *Putting People First* and beyond, councils should have both a strong focus on the overall well-being of their communities and a recognition that people should be helped in a way that may prevent, reduce or delay their need for social care support. This shift in focus to community well-being and preventative approaches is also fundamental to the effective application of eligibility criteria. There is a growing evidence base that interventions can prevent or delay people entering the social care system and therefore produce better outcomes for people at a lower overall cost.

This review paper presents some evidence for early intervention and its connection with better outcomes for both carers and those they support. There are five key messages for health, social care and other agencies:

- Early intervention is integral to personalisation.
- Applying early intervention thinking to the support of carers can lead to better value for money and better outcomes.
- There is an evidence base to support the claim that carer support can create savings for adult services.
- Considering carer support in the context of major care pathways such as hospital discharge, falls, dementia and stroke could generate systems-wide efficiencies.
- Systematic information collection from service users and carers would improve the evidence base and improve the investment of limited resources in both health and social care.

This paper builds on learning from the Partnerships for Older People Programme [POPPS] and reflects the approach being considered by the Care Quality Commission to Assessments of Quality for commissioners and providers of health and social care<sup>5</sup>. The CQC paper contains an underpinning statement that informs the key messages set out above and is reflected in this paper:

*“It is also clear that there are significant opportunities for better outcomes for people, and for taxpayers” by getting health and social care services to work more effectively together...” [p.17]*

We believe this paper will contribute to the work of local commissioners and their partners to achieve this. It is offered for discussion, development and consideration for local action.

## 2 - INTRODUCTION

In 2009 the Princess Royal Trust for Carers and the Association of Directors of Adult Social Services [ADASS] were part of a collaboration which published linked papers on the implementation of *Putting People First*<sup>6 7</sup> and on commissioning support for carers. This paper builds on that work.

### 2.1 The context

The Government makes available to local areas around a quarter of a billion pounds a year to spend on support for carers. An additional £150m was identified in the 2008 National Carers' Strategy in Primary Care Trusts' base budgets. A great deal of this resource is targeted at preventing carers suffering reduced well-being, health or employment prospects, or mitigating those ill effects and reducing the need for expensive statutory support.

This paper focuses on how early intervention and support for carers can lead to better outcomes both for carers and for the person supported. These interventions also tend to lead to better value for money. Much of the paper is concerned with support for older people, but as many carers are older people themselves or are working age people (and occasionally children) who care for an older person, the evidence presented has relevance to adult carers of all ages.

### 2.2 Themes

Much of the evidence of outcomes achieved by earlier intervention is relevant to three major conditions, which primarily affect older people::

- Dementia
- Falls
- Stroke

We also look briefly at hospital discharge and carers where a separate ADASS paper was produced in 2010<sup>8</sup>.

Within each of these areas there is an established national policy framework to guide local action. These national frameworks are summarised in **Appendix A**. They are:

- Putting People First [December 2007] <sup>4</sup>
- Carers at the heart of 21<sup>st</sup> Century families and communities [June 2008]
- National Dementia Strategy [June 2009]<sup>9</sup>
- National Stroke Strategy [December 2007]<sup>10</sup>
- Implementing National Service Framework for Older People – Standard 6 [September 2003]<sup>11</sup>

In addition, as noted in the Key Messages section, updated guidance<sup>3</sup> on eligibility criteria for adult social care issued in March 2010 (replacing Fair Access to Care guidance) has some strong messages in this area. This guidance makes clear that councils should ensure their application of eligibility criteria is located against a backdrop of strong and supportive communities and where the wider context of personalisation, including a strong emphasis on prevention, early intervention and support for carers is in place. More information is given in **Appendix B**.

### 3 - IDENTIFYING RELEVANT OUTCOMES

#### 3.1 Defining early intervention and prevention

The 2008 National Carers' Strategy recognises the value of early intervention and responsiveness when a carer experiences a crisis. It states that:

*“By preventing breakdown of the valuable support that carers provide, not only is the financial cost of repairing carers' own health avoided, but the additional cost of providing alternative care for the people they are supporting is avoided too.” [3.10]*

**All Our Tomorrows**<sup>12</sup> published in 2003, outlined proposals for “inverting the triangle of care”. It identified two broad definitions for prevention:

- Services which prevent or delay the need for more costly intensive services; and,
- Services and approaches that promote quality of life and engagement in the community.

In proposing a broader perspective, it was recognised there was interdependence between the two approaches. For example, fears around falling and concerns around the ability to get assistance when it happens can be a factor leading to admission to care homes. This can be a considerable source of concern to relatives<sup>13</sup> who may then wish for more intensive support. In contrast, making telecare more widely available at an earlier stage, for example, can make a real contribution to sustaining care at home and reducing carers' anxieties. More effective assessment and response mechanisms, which consider impacts upon carers, can also improve independence and well-being outcomes for both the individual and their carers, reducing the demand for statutory services.

**Commissioning for Carers**<sup>14</sup>, notes that commissioning to achieve better outcomes for carers is complex, because carers both supply and (in many cases) need care and support. So whilst carers are every area's most significant source of care and support, making up around 10% of an area's population,<sup>15</sup> within that group, there will be a number of carers, including some of the million who give the most care and support (fifty plus hours per week), who require significant support themselves. So early intervention in the context of carers is two fold:

- Interventions aimed at helping carers to sustain a caring role and avoid a crisis that might adversely affect or end it (e.g. information, training).
- Interventions aimed at improving the carer's wider well-being, as individuals in their own right (e.g. breaks, support to access employment).

In both cases, an intervention may be delivered directly to the carer, or indirectly through providing increased, or more carer-friendly, support to the person receiving care.

Sometimes it could appear that there is a contradiction between reducing the risk of the caring role ending and increasing a carer's well-being, particularly where the caring role appears to represent the most significant risk to the carer. Certainly no one is, or should feel, obliged to take on caring responsibilities and in some cases it may be felt that the best outcome for the carer is for them to reduce or end their caring role. This decision is best taken however, when support has been offered to make a caring role more manageable. This can be achieved in some cases by ensuring carers are fully involved and consulted during care planning decisions.

What is needed is an improved ability to identify the triggers or tipping points to more intensive help, moving beyond a narrow consideration of clinical factors or the individual in isolation, towards seeing the individual in their family and community context, recognising also the roles of housing, leisure, transport and other agencies. The evidence in this paper, then, has relevance for Regional Improvement and Efficiency Partnerships and Joint Improvement Partnership frameworks.

### **3.2 The value of early intervention**

It is well-established, for instance by *The Wanless Report*<sup>16</sup> [2006], that resource decisions should be linked to evidence of the achievement of outcomes. An outcomes approach can be both an incentive and a barrier to change, particularly where savings in one service budget can only be achieved by costs in another. It is vital, therefore, to look across whole systems and complete care pathways.

For example, those who have no carer are more likely to be admitted to care homes<sup>17</sup>. Carer-related reasons for admission to nursing or residential care are common, with carer stress the reason for admission in 38% of cases and family breakdown (including loss of the carer) the reason in a further 8%.<sup>18</sup> A number of support, housing, financial and employment factors can contribute to the practical and emotional viability of caring roles and lower rates of admission to care homes.

## 4. ALIGNING SYSTEMS TO OUTCOMES

### 4.1 Individuals & Families as Experts

In looking at these issues we must retain a focus on people's preferences about the care and support they receive. Most older people prefer to receive care at or close to home.<sup>19</sup> This was established, for instance, in *Living Independently* 1994, *Later Lifestyles*, 1999 and *Securing Good Care for Older People*, 2006, which found however, that many older people still found themselves in a care home. Family members were often influential in the decision making and the presence of and support for carers could delay admission to care homes and have a positive impact on the quality of care for the supported person [p147 -148].

### 4.2 Making a Start

Research suggests that "carers play a key role in both the initial decision to seek long-term care, and in selecting a home" but, significantly, that "carers rarely experience a move to long-term care as desirable or a positive choice"<sup>20</sup>. So identifying carers and supporting them to maintain their caring, working and family life is likely to result in less uptake of residential care and outcomes more in line with the preferences of older people (see previous section).

A working consensus on the complete range of carers' interventions needed in any one area is presented in *Commissioning for Carers* and reproduced in **Appendix B** alongside a quality of life model, developed by the Association of Directors of Adult Social Services [ADASS]. The key message of these models, that improved outcomes depend on a range of inter-dependent interventions, is also reflected by the National Stroke Strategy model of support reproduced in **Appendix A**.

At the same time we must recognise that the range of supports available is constantly growing and changing. This needs to be allowed for at local level when applying any of these models. In general terms, the elements which every area needs to have in place are to:

- ensure that carers are involved in planning, commissioning decisions and service design;
- find carers, particularly those most often overlooked, through outreach, partnerships and co-located services;
- provide tailored information and advice;
- support carers to be involved in community care planning particularly at the point of hospital discharge, providing carer advocacy where needed;
- support carers to plan for their own lives, including planning for emergencies;
- target additional or specific support for older people upon those whose carers will also benefit;
- provide emotional, practical and peer support; including carer training;

- provide breaks and opportunities to take up employment and leisure activities;
- help carers to use health and support services which they need themselves;
- gather systematic and regular feedback of the outcomes experienced by users and carers, with a focus on independence, well-being and a sense of having a real say and being in control;
- share feedback on outcomes with health, social care and other agencies.

In Section 5 we set out how these kinds of interventions can be pursued. In developing local support frameworks a “questioning approach” can be very helpful in assessing whether what happens works for carers and in developing a stronger and essential focus on outcomes. For example:

- What is the success of hospital discharge for people who receive care (measured in terms of emergency re-admissions within 28 days)?
- How can we improve the proportion of discharges to home rather than to residential care?
- What are the proportions of older people with support needs who live at home and in a care home and should these changes?
- Who are the most excluded and overlooked groups?

In terms of the areas we have been looking at:

- **Stroke:** what is the impact of supporting carers to plan and of providing carer training from the time of stroke onwards?
- **Dementia:** what is the impact of providing training for carers at pre-diagnosis and whilst the person’s dementia is below the threshold for statutory support?
- **Falls:** what is the impact upon the sustainability of home-based care, carer employment and the rate of hospital admissions of providing falls risk assessment, prevention, risk reduction and recovery support both for older carers and for older people who receive care from their families?

### 4.3 More Evidence on Needs and Outcomes

Local bodies need to collect systematic evidence to inform commissioning. Carers and people supported by them should have a real say about what outcomes matter and both population and performance outcomes should be a feature of Joint Strategic Needs Assessments. We deal with these issues in more detail in the next section and in a separate paper<sup>21</sup>.

## 5 - EVIDENCE - OUTCOMES CARER INTERVENTIONS

### 5.1 Earlier Identification & Inclusion

*Commissioning for Carers* identifies some distinct kinds of carer interventions. These include direct support to those carers in most need. They also include universal services which can identify, include and inform carers, whatever their level of entitlement. Over two million people move in and out of caring every year<sup>22</sup>. Identifying carers will be a crucial part of early intervention and prevention. Identification can involve specialist workers located in GP practices, hospital wards, mental health services, substance misuse services, housing associations, schools, shopping centres or other community settings.

This may occur prior to any diagnosis of the cared-for person. For example, on average, it takes three years before someone who develops dementia is diagnosed. During this time they may well be building a dependency upon a carer who lacks the entitlement to benefits and who may have been reluctant to seek advice or support or does not understand the condition<sup>23</sup>.

The Carers' Resource in Harrogate, Craven and Airedale, a member of The Princess Royal Trust for Carers network, has produced some compelling evidence showing how treating carers as partners in care uncovers and meets unmet need. They found that listening/emotional support, followed by personalised information, topped the list of priorities for the carers they supported. The chart below demonstrates the huge difference in numbers of carers identified each year by GP practices (y axis), according to the level of partnership between the GP practice and the Carers' Centre.

Further examples can be found in an *Action Guide for Primary Care*, published by The Princess Royal Trust for Carers and Royal College of General Practitioners at [www.carers.org/professionals](http://www.carers.org/professionals)

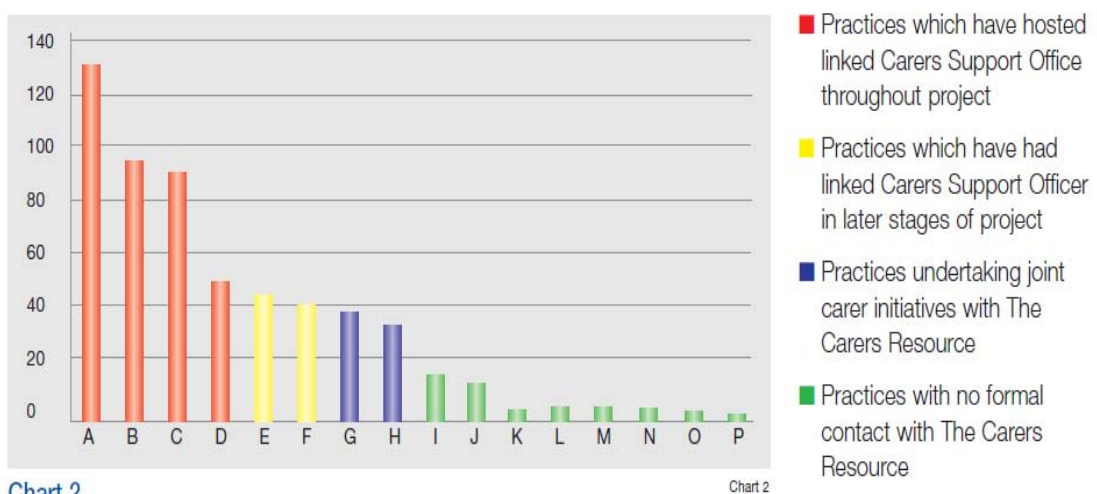


Chart 2

Chart 2

The Carers Resource carers registered at Airedale practices

## 5.2 Tailoring Information & Advice

In 2003, an Omnibus Survey of a representative sample of Cardiff residents<sup>24</sup> found information and advice was the most desired form of help. Nearly 50% of carers wanted this kind of help, with the provision of equipment or aids second at 30%.

Carers in Hertfordshire<sup>25</sup> undertook research with carers in one GP practice in their area. They compared outcomes for a sample of carers who had been referred to the carers' centre for information and support with those who had not. Carers who were referred were twice as likely to feel well informed about rights and services and to know what to do in a crisis. They were more likely to have had a recent break and more confident about accessing care services, leisure, education or work.

As the research cited in this review suggests, these impacts are likely to help carers sustain their caring role. The POPPs evaluation report<sup>26</sup> is also supportive of the added value flowing from this sort of work.

*A Systematic Review of Interventions for Carers in the UK: Outcomes and Explanatory Evidence*<sup>27</sup> found that, alongside effective statutory carer assessments, provision of CSWs and information services (usually commissioned from the third sector) can successfully provide carers with emotional support and increased access to services. Factors which appeared to influence their success included flexibility and tailoring of the service and continuity of support with enough time to build up support relationships.

It could be difficult to achieve outcomes, however, if there was a mismatch between the service and the carer's cultural or family dynamics; or between the participants and service providers' perceptions of the service; or between the wishes of the carer and the person receiving care.

## 5.3 Recognising that Carers are Partners in Care

The most significant impact on the sustainability of a caring role can often be achieved by improving the support given to the person receiving care. This can mean increasing the quantity of support. Equally, it can mean ensuring that services have been planned to complement and support the care given by families or friends. This can often be greater than that provided by the state. For example, the timing of care provision may need to be planned not only to maximise an individual's access to employment or their community, but also to maximise their carer's opportunity to work or carry on working.

In March 2010, ADASS published a paper reviewing how far carers were partners in hospital discharge. The National Carers' Strategy is clear that carers should be treated and respected as expert partners in caring and have access to integrated and personalised services to support them. The review shows how accessible and available information can make a real difference and that carer support workers can improve outcomes for carers and patients.

Two pieces of work drawn upon as part of this review were the “**Out of Hospital Project**”<sup>28</sup> and the “**Crisis Prevention for Carers Project**” [Moffat]<sup>29</sup> (both commissioned by the Princess Royal Trust for Carers) which provide valuable evidence of how to focus on better outcomes through improved recognition and involvement of carers.

**Predictors of institutionalisation in people with dementia**<sup>30</sup> was a longitudinal study of 100 people and their main family carer in south London, aiming to identify what patient and carer characteristics influence transition into residential care for people with dementia. The most striking finding is the 20-fold protective effect of having a co-resident carer. The need for residential care was also reduced when there were no behavioural problems and when the carer was psychologically healthy. The researchers said:

*“...interventions directly targeted at helping [carers] to maintain this role would be supported by these data. These data also suggest that strategies directed at improving carer quality of life and at the resolution of behavioural disorder in the person with dementia may also have particular value”.*

#### **5.4 Emergency Support**

Research into the effectiveness of approaches to emergency support planning is at an early stage<sup>31</sup>. Typically, however, whilst little respite care is actually drawn upon, large numbers of registered carers report significant increases in peace of mind, meaning that the unit cost of such schemes can be very low and carer satisfaction high. Failure to avoid an emergency admission for the person being cared for could have long term consequences and costs.

Sadly, the built up pressures of caring may mean once someone has been admitted to hospital, a refusal of their carer to allow them to return home can be “a common point of admission” to nursing care<sup>32</sup>. Equally, several studies show that “medical practitioners and social workers can be particularly persuasive; expressing the view that admission to a care home is the only realistic solution”<sup>33</sup>. Time frames for making these decisions can be limited and the longer term costs high.

#### **5.5 Linking Support for People who Receive Care to Outcomes**

Telecare and telehealth have the potential to achieve better outcomes for carers as outlined in *The Gift of Peace of Mind* in 2005<sup>34</sup>. A Scotland Government report has considered the impact upon carers of providing Telecare to people with dementia, learning disabilities and others<sup>35</sup>. It indicated that nearly three quarters of carer respondents felt that telecare equipment had reduced the pressure on them by reducing stress levels; with only 4.3% feeling that their stress levels had increased.

Families and carers had greater peace of mind as they worried less (e.g. about falls and risks).

The report suggested that people with learning disabilities could enjoy greater independence whilst people with dementia could remain living in the community for longer. Where stress levels had fallen, several respondents highlighted that caring nevertheless was still very demanding and stressful (especially if the client would not use the new equipment). There are three valuable outcomes here: caring is sustained; people continue to live independently and fears for well-being and safety reduced. Feedback from carers suggests these are important outcomes.<sup>36</sup>

One randomised controlled trial (RCT)<sup>37</sup> looked at the effects on carer distress of an additional specialist clinical assessment for vulnerable older people at risk of residential placement. The study found this could be effective in reducing carer distress by targeting services towards the distressing behaviours of the person for whom they cared. This was particularly so where the older person had symptoms of depression.

## **5.6 Individual, Group & Peer Support**

A significant correlation between caregiver burden and increased use of mental health services has been widely noted<sup>38</sup>.

As with other groups, there is also a significant positive correlation between anxiety and depression and primary health care use amongst carers. Professor Sube Banerjee of Kings College London has noted that “there is now a large literature attesting to wide-ranging potential benefits of carer interventions in dementia,”<sup>39</sup> including psycho-educational interventions; carer training; psychological therapies such as cognitive behavioural therapy (CBT) and respite care. Systematic reviews and meta-analyses<sup>40</sup> suggest that such interventions seem to reduce carer strain and carers’ depression and anxiety, with the largest impact on the latter from CBT. There is no universally effective intervention, however, and all interventions need to be tailored to differing condition groups, carer communities and stages of caring.<sup>41</sup>

Torbay Care Trust<sup>42</sup> commissioned Manchester PSSRU to evaluate the use of Carers Support Workers (CSWs) in GP surgeries in 2002. CSWs typically advise or train primary care staff in carer-awareness and/or provide direct advice, advocacy and emotional support to carers themselves. General Health Questionnaires (GHQ) were used with 68 randomly selected carers. Whilst over half of the carers said that they were in good health, GHQ scores indicated almost all were suffering significant mental distress. After support from a Carers Support Worker, the proportion of carers who could be identified as symptomatic cases fell by 21%. In particular, the proportion of carers having problems with concentration and sleeplessness reduced substantially.

*A Systematic Review of Interventions for Carers in the UK*<sup>43</sup> did find evidence that carer support groups could lead to a wide range of outcomes including:

- receipt of information and advice on a range of topics;

- emotional support from other group members and through the development of confidence and a carer identity;
- social inclusion through meeting others, developing friendships and participating in social activities and outings; and,
- in some cases, facilitation of access to other services.

It found that groups aimed at carers of a particular type (for example, those caring for people with a mental health difficulty) provided greater emotional and social support to members than more generic groups. The *Review* concluded that it might be helpful for local areas to review the number and range of different groups available and to consider gaps in provision and outcomes for local carer populations.

## 5.7 What Emotional, Practical & Peer Support Can Do

Whilst tackling poor carer well-being is clearly beneficial in itself, many findings suggest that there can also be savings in reduced uptake of residential care. The Office for National Statistics<sup>44</sup> found that a third of carers (35%) without good social support suffered ill-health compared to those with good support (15%).

A US evidence review<sup>45</sup> found that although variables in caring situations impact upon each care-giving situation differently, “decreased functional abilities of the care receiver, interrupted sleep of the caregiver” and increased complexity of the caring situation were positively correlated with caregiver burden. So were the need to give continuous supervision and a lack of breaks.

Carers who were aged 54 and over had increased risks due to physical caring tasks. Those who were younger than 54 experienced a greater emotional burden. These various increases in the ‘caregiver burden’ were correlated to an increased risk of nursing home placement. Various studies suggest that the carer’s gender, income and social class do not appear to be significant risk factors. For older people from black and minority ethnic communities, however, carer difficulties are more likely to feature among the list of reasons for care home admission than for white people.<sup>46</sup>

***A family intervention to delay nursing home placement of patients with Alzheimer disease***<sup>47</sup> was a randomized controlled trial of 206 spouse carers in the USA. The study found that those whose carers had received six sessions of individual and family counselling, support groups and access to additional counselling on demand, on average spent almost a year longer at home before needing residential care. The study was extended over a 9.5 year period and to 406 spouse carers. The initial sessions were followed by continuous availability of telephone counselling. This extended study<sup>48</sup> found that the average increase in time able to be spent at home prior to needing residential care was over 500 days.

***Predicting who will need costly care***<sup>49</sup> noted the value of gathering information relating to carers in making predictions. It points to the value of routine predictive tools to target preventive interventions for some of the areas identified in this paper. A specific predictive tool for carers could be helpful.

An Australian study showed that 10 sessions of training (focused on distress and isolation reduction, coping skills, fitness and diet) for carers of people with dementia, which included social and leisure activities, “delays admission to a nursing home by an average of 20 months.”<sup>50</sup> A UK RCT in 2004,<sup>51</sup> to assess the effectiveness of providing basic nursing and facilitation of personal care training to carers for stroke patients, found no impact on institutionalisation of patients. After twelve months significantly lower costs (average of £10,133 vs £13,794) were observed, however, in the intervention group, mainly due to reduced hospital costs, with some home care costs. There were also significant reductions in carer burden and improvements in mood and quality of life for carers and care recipients.[see also: POPPs projects below]

The expert carer programme, launched in 2008 as ***Caring with Confidence***<sup>52</sup> as part of the National Carers’ Strategy, is expected to generate new evidence about the effectiveness of training, learning and advice.

## **5.8 Impact of Breaks Services**

A dementia study found that breaks services can lead to significant reductions in carer strain and psychological morbidity.<sup>53</sup> In a ***Research in Practice*** summary of the cost-effectiveness of various kinds of carer support, Pickard notes that “both day care and residential respite care have positive outcomes for carers.”<sup>54</sup> The examples given include day care reducing stress for about 85% of carers (particularly for those caring for severely cognitively impaired older people and for carers in paid employment) and increases in home care reducing stress among carers of older people<sup>55</sup>.

There is mixed evidence on the impact of the uptake of breaks upon nursing home use. This may be because carers tend to require more breaks as caring roles become less manageable. In some areas, carers can only access breaks at high levels of need. Some studies have shown both that use of respite delays nursing home placement<sup>56</sup>. For some older people, however, residential respite care can increase the probability of permanent admission<sup>57</sup>.

An RCT that looked at a Dutch programme of day care based respite, coupled with carer support and advice, found that the programme achieved significant delays in transfer to residential care.<sup>58</sup> Care home admission could, of course, be the most appropriate solution for some families but is not always the preferred option or choice. More data are needed on the admission triggers.

## **5.9 Reducing Carers’ Inequality of Access to Services**

The National Carers’ Strategy notes that “Carers often find that their caring responsibilities prevent them from accessing health services both for their own needs and on behalf of the person they support” (p106).

Some Primary Care Trusts [PCTs] and GP practices have put initiatives in place, such as preferential access to GP appointments, home visits and telephone support. The aim is to increase uptake of primary care services by carers and reduce risk of health crises, but there has been little evaluation of these outcomes.

### **5.10 Carers' & Dementia Strategies' Demonstrators**

The National Carers' Strategy Demonstrator Sites programme<sup>59</sup> aims to provide new evidence on support for carers in health settings, better NHS partnerships, providing carers with health checks and cost-effective approaches to the provision of breaks. The evaluation should be available in 2010/11.

As part of the implementation of the Dementia Strategy, the Department of Health is funding a number of demonstrator sites testing the effectiveness of peer support approaches and dementia advisors. Similarly, the Carers' Strategy raises the idea of providing all carers with a lead professional. The impact upon carers as well as upon people with dementia will be measured by evaluations which will report in 2011.

### **5.11 Partnerships for Older People Projects**

The Partnerships for Older People Projects [POPPS] were funded by the Department of Health to develop services for older people aimed at promoting their health, well-being and independence and preventing or delaying their need for higher intensity or institutional care. The final report of the national evaluation was published in January 2010<sup>26</sup> and demonstrated prevention and early intervention can work for carers.

The focus of the evaluation was on outcomes and processes. Older people and to some extent their carers were involved throughout the evaluation. The projects covered primary, secondary and tertiary levels of prevention. One stream of projects was concerned with supporting carers. There were also projects looking at hospital discharge and falls. Those who lived alone were shown to have a higher take-up of higher level services [p123]. There was only one project concerned with expert carers and the evidence was that following the interventions they were coping better and, by implication, better able to continue their caring role; although there were still real needs for respite and sitting services.

Small services providing practical help and emotional support can significantly contribute towards improved health and well being, alongside services expressly directed towards avoiding the need for hospital. Both are key areas for carers.

In the longer term, the project pointed to the potential for greater value to be secured. At the same time the reminder is given that unless cashable savings can be released and reinvested [along care pathways] then the full benefits may not be realised.

## APPENDIX A

### WIDER POLICY BACKGROUND

#### 1. National Strategy for Carers [2008]

The cross government national strategy for carers published in 2008 replaced the earlier national strategy prepared in 1999. It formed part of a suite of interlinked policies within a public sector reform process intended to lead to better joined up working, value and outcomes for people and communities.

The vision of the new national strategy for carers was that by 2018

*“... carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals’ needs enabling carers to maintain a balance between their caring responsibilities and a life outside caring, whilst enabling the person they support to be a full and equal citizen”.*

The key outcomes, which are at a high level, the Government sought were:

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

#### 2. Putting People First [2007]<sup>4</sup>

In December 2007 a national concordat, **“Putting People First”**, was published. This has provided the framework for a transformation agenda that includes:

- ❑ Giving most people who receive funded care their own personal budgets;
- ❑ Much closer collaboration between NHS and local government;
- ❑ A focus on early intervention and prevention;
- ❑ Investing in support that tackles loneliness and isolation; and,
- ❑ Joint strategic needs assessments undertaken by local authorities, Primary Care Trusts and NHS providers.

**Putting People First** makes clear that personalisation is linked to investment in all aspects of support for people and their carers. This includes:

- *Universal services* – the general support available to everyone within their community including transport, leisure, education, employment, health, housing, community safety and information and advice.
- *Early intervention and prevention* – helping people live at home independently, preventing them from needing social care support for as long as possible and potentially creating future cost efficiencies.
- *Choice and control* – giving people a clear understanding of how much is to be spent on their care and support and allowing them to choose how they would like this funding to be used to suit their needs and preferences.
- *Social capital* – fostering strong and supportive communities that value the contribution that each of their citizens can make.

It is recognised that when resources are tight there is a need to look at innovation and how interventions beyond the traditional boundaries of adult social care can help to delay or avoid the need for support. Key milestones are now in place. Progress will be measured by whether everyone will be able to:

- live independently
- stay healthy and recover quickly from illness
- exercise maximum control over their own life and, where appropriate the lives of their family members
- sustain a family unit which avoids children being required to take on inappropriate caring roles
- participate as active and equal citizens, both economically and socially
- have the best possible quality of life, irrespective of illness or disability and
- retain maximum dignity and respect.

**Source:** LAC (DH) (2010) 1 – Transforming Social Carer – the Social Care Reform Grants, Department of Health, 29 March 2010.

The potential contribution of Joint Strategic Needs Assessments has been recognised. The need to link to other strategies around housing and sustainable communities is also emphasised in the guidance.

### **3. National Dementia Strategy [2009]**

Prevalence of dementia rises rapidly with advanced age. Adults over 85 are significant users of hospital inpatient provision. Up to 70% of hospital beds are occupied by older people and up to half of these may have cognitive impairments. **“Living well with Dementia: A National Dementia Strategy”** is an important step forward in improved recognition, support and quality care for people with dementia in England. It links with the principles in **“Putting People First”**. It has three themes around improved public and professional awareness, early diagnosis and support. The strategy has 17 key objectives that describe the range of services that people with dementia and their carers should be able to access. These include:

- Good quality information for those diagnosed with dementia and their carers
- Services within the Carers’ Strategy

The core principles for commissioning dementia services within the strategy include:

- keeping the person with dementia and their carers at the centre of all commissioning activity;
- working across the commissioning community for a joined up care pathway for people with dementia and their carers;
- building quality and dignity into every service; and,
- advocacy to help people with dementia and their carers to obtain services and to get their views across.

#### 4. National Stroke Strategy [2007]

Stroke has lasting impact on people's lives and those who support them. Every year approximately 110,000 people in England have a stroke of whom one third die within three months. Stroke is the largest cause of adult disability with 300,000 people living with moderate or severe disability as a result of a stroke. It sets a framework of quality markers [QMs] for raising the quality of stroke prevention, treatment, care and support over a ten year period. It has a ten point plan for action:

<ul style="list-style-type: none"> <li>• Awareness</li> <li>• Preventing Stroke</li> <li>• Involvement</li> <li>• Acting on warnings</li> <li>• Stroke as a medical emergency</li> </ul>	<ul style="list-style-type: none"> <li>• Stroke unit quality</li> <li>• Rehabilitation and community support</li> <li>• Participation</li> <li>• Workforce</li> <li>• Service Improvement.</li> </ul>
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Chapter 3 recognises the importance of carers. The aim is that;

*“For those who have had a stroke and their relatives and carers, whether at home or in care homes, to achieve a good quality of life and maximise independence, well-being and choices.”*

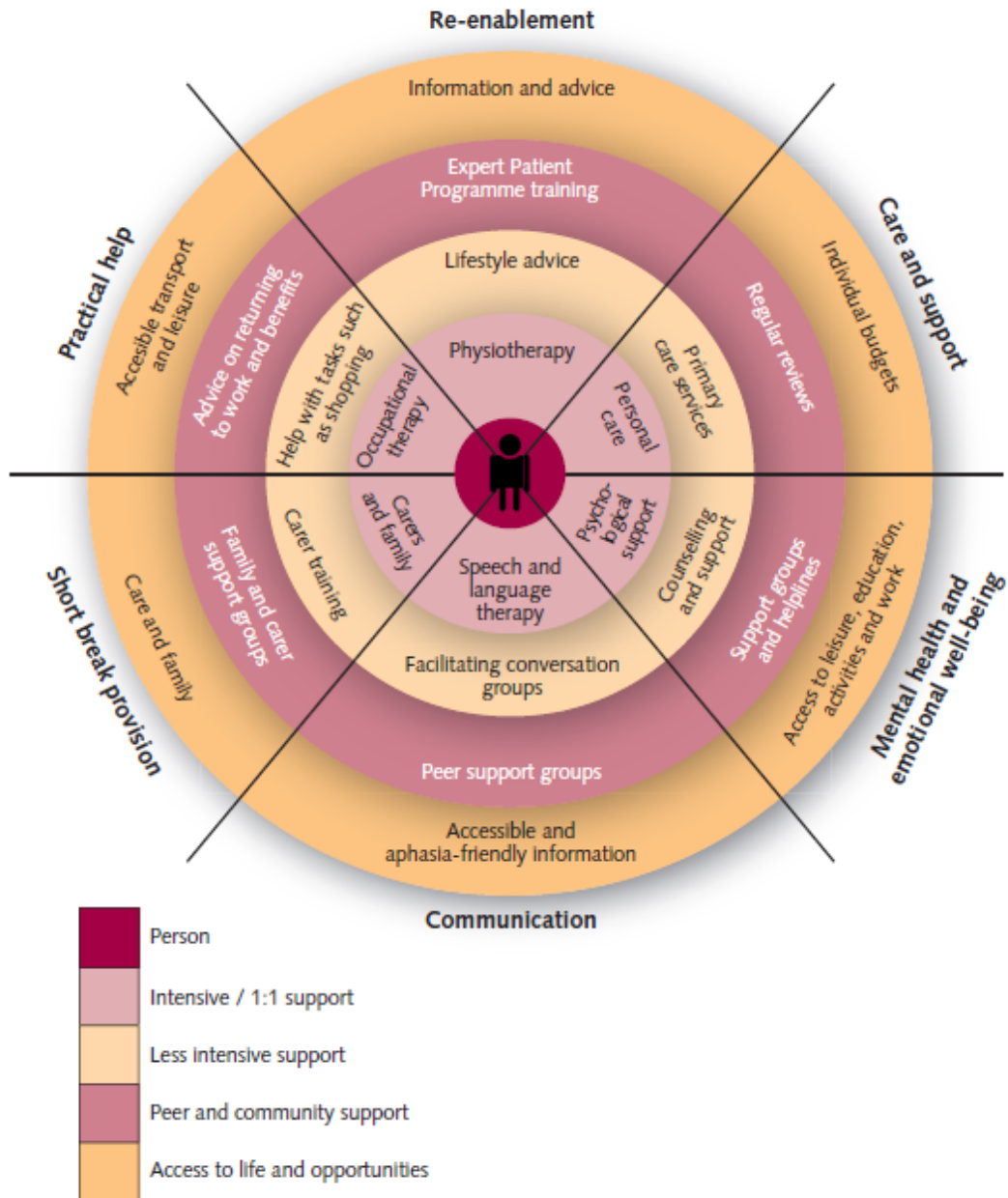
Ensuring the correct type and levels of support for those who have had a stroke and their carers is a key area of challenge for commissioners and for providers of care and support. The national strategy goes on to state:

*“ carers are vital in providing support for people who have had a stroke and medical professionals and providers must acknowledge this when looking at the long term support for people who have had a stroke. Carers are entitled to an assessment in their own right for support and access to ongoing, long term support service such as planned short breaks and laundry and continence support services can enable carers to sustain care at home over the long term.” P.44*

Chapter 3 includes a diagram setting out the range of support services someone might need after a stroke. This recognises the important contribution of carers and is reproduced overleaf.

**DIAGRAM 1**

**The range of support someone may need after a stroke**



**Source:** Department of Health, *National Stroke Strategy*, DH, December 2007  
Chapter 3 p 49

## **5. NSF Older People Falls Standard 6 [2003]**

Standard Six of the National Service Framework [NSF] for Older People 2001 aims to;

*“Reduce the number of falls which result in serious injury and ensure effective treatment and rehabilitation for those who have fallen”.*

The standard envisages that integrated falls services would help to improve care and treatment of those who have fallen. In September 2003 the Department of Health issued policy guidance on implementing the falls standard. The intention was to support the commissioning of effective services. This included an emphasis on the following:

- Including Older people’s perspectives
- Building on the care pathway approach
- Specifying defined local outcomes, outputs and timescales
- Integrated evaluation
- Multi agency commitment
- Building on small beginnings

## APPENDIX B

### **GUIDANCE ON ELIGIBILITY CRITERIA FOR ADULT SOCIAL CARE MESSAGES ON CARERS, YOUNG CARERS AND EARLY INTERVENTION**

The strategic vision of the National Carers' Strategy is embedded into this statutory guidance which was issued in March 2010. Published by the Department of Health its full title is;

*Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care. **Guidance on Eligibility Criteria for Adult Social Care, England, 2010.*** [3]

#### **Messages for Carers**

There is a whole section on Carers within the guidance. It points up the importance of identifying all needs and not just eligible needs. The guidance confirms that where someone has needs and a carer is willing to meet some but all of those needs, a council should "... provide a response to address those eligible needs, which are those needs not being met by the carer." [94]

The guidance reminds Councils that they should not make assumptions about the amount and quality of support available from carers. It states:

*"Inappropriate assumptions about how much support carers are willing and able to provide can lead to an underestimation of potentially eligible needs."*

The right of certain carers to have an assessment is restated and the twin purposes of carer's assessments are described as follows:

*"The first is to consider the sustainability of the caring role. The second is to consider whether or not the carer works, wishes to work and whether or not the carer is undertaking or wishes to undertake education, training and leisure activity, and the impact of their caring role might have on these commitments or aspirations."* [97]

#### **Outcomes & Early Intervention**

Councils are encouraged to base their approach to needs on achieving outcomes rather than providing specific services. It reaffirms the need to identify any children and young people acting in a caring role and consider the impact on them. It confirms that community care packages should not rely on the input of an inappropriate level of care from a child or young person.

In terms of early intervention this document reaffirms some key messages. At paragraph 4 it states:

*"... councils should ensure that the application of eligibility criteria is firmly situated within this wider context of personalisation, including as strong emphasis on prevention, early intervention and support of carers."*

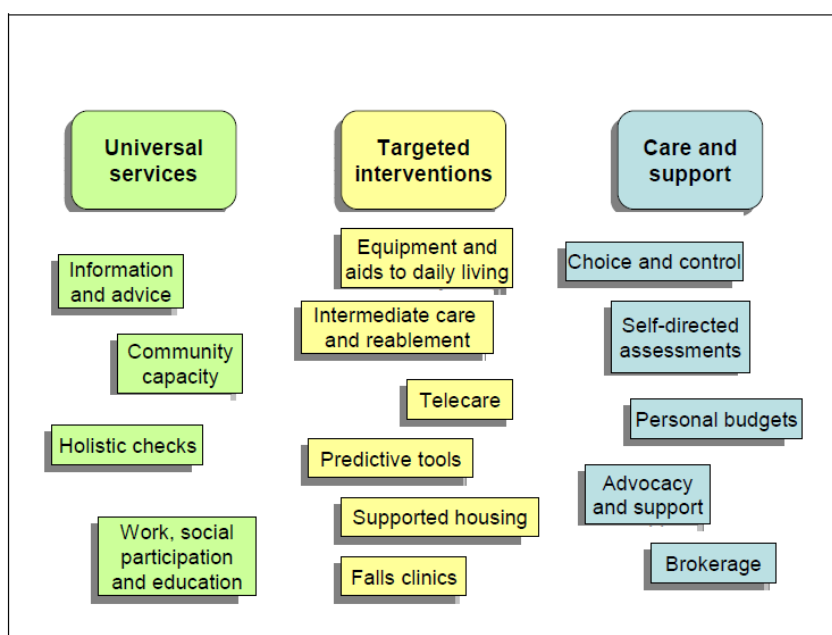
Prevention and early intervention are seen as being “at the very heart” of the government’s vision for adult social care. Councils are encouraged to consider whether providing support to carers would reduce the need for more intensive support. It reaffirms the messages from ***Cutting the Cake Fairly [2009]***, prepared by the Commission for Social Care Inspection. These are that councils need to avoid being too restrictive about what kinds of support they make available and where flexibility can result in a caring role being maintained and longer term independence and well being confirmed:

*“... There is a growing evidence base around interventions that can prevent or delay older people in particular from needing social care, although much work still needs to be done in this area. Low cost interventions may also have a considerable impact on day-to day quality of life.”*

The types of resources and services that come into play in the section on investing in prevention and well-being are set out in figure 1 [page 17] below:

**Figure 1**

**Types of resources and services**

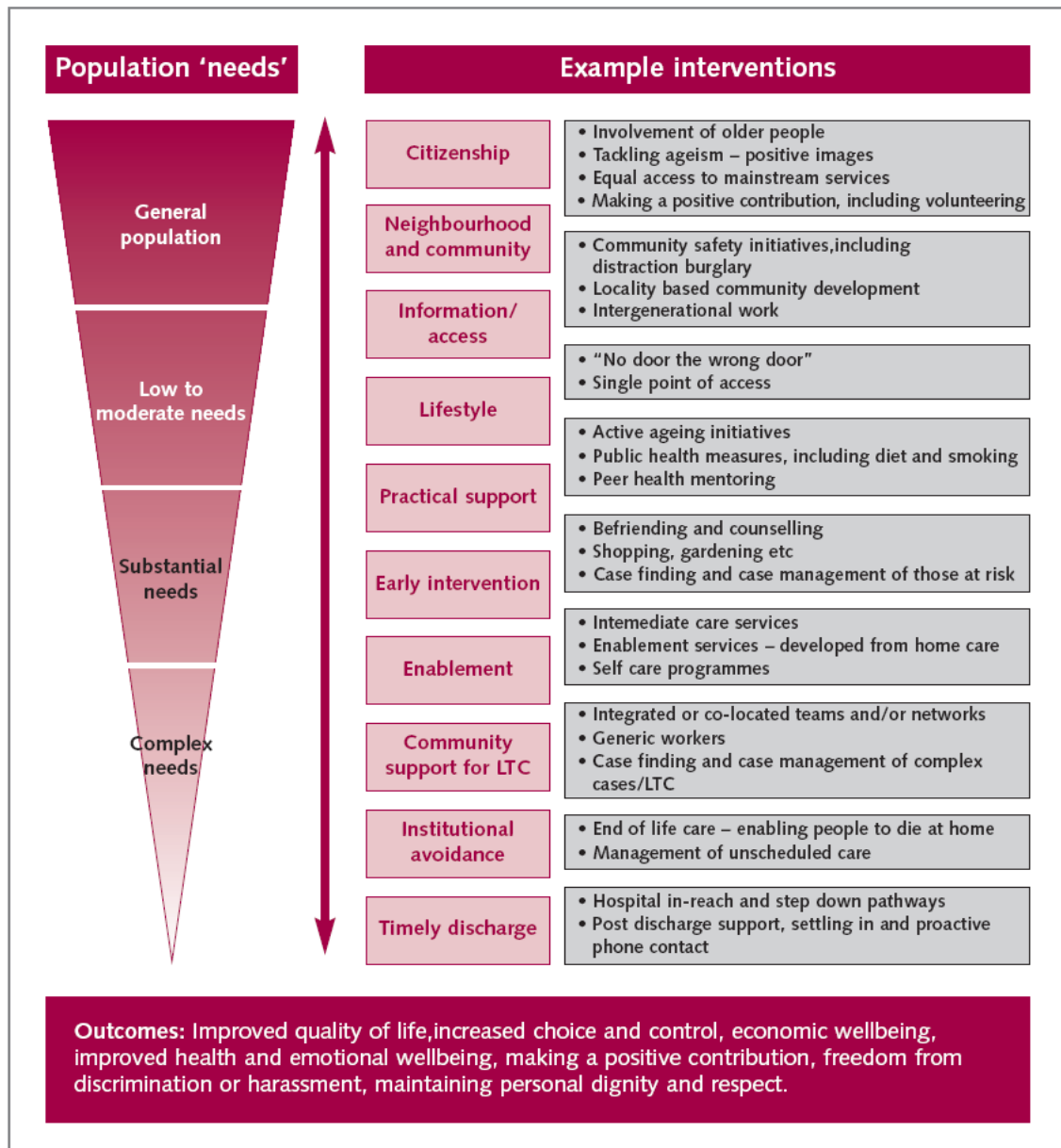


Source: as stated

The guidance also offers a number of reminders on the need for proportionate assessment arrangements and the need for transparency and consistency in the allocation of resources. The guidance also refers back to an earlier publication: ***“Making the strategic shift towards prevention and early intervention: Key messages for decision makers, [October 2008].*** This paper was aimed at supporting key decision makers and commissioners across health and social care to invest “with confidence” in a balanced range of effective preventative approaches for older people. It made use of emerging information from the POPPs programme. A diagram from that document is reproduced in full overleaf.

Figure 2

## Needs, Interventions and Outcomes [2008]



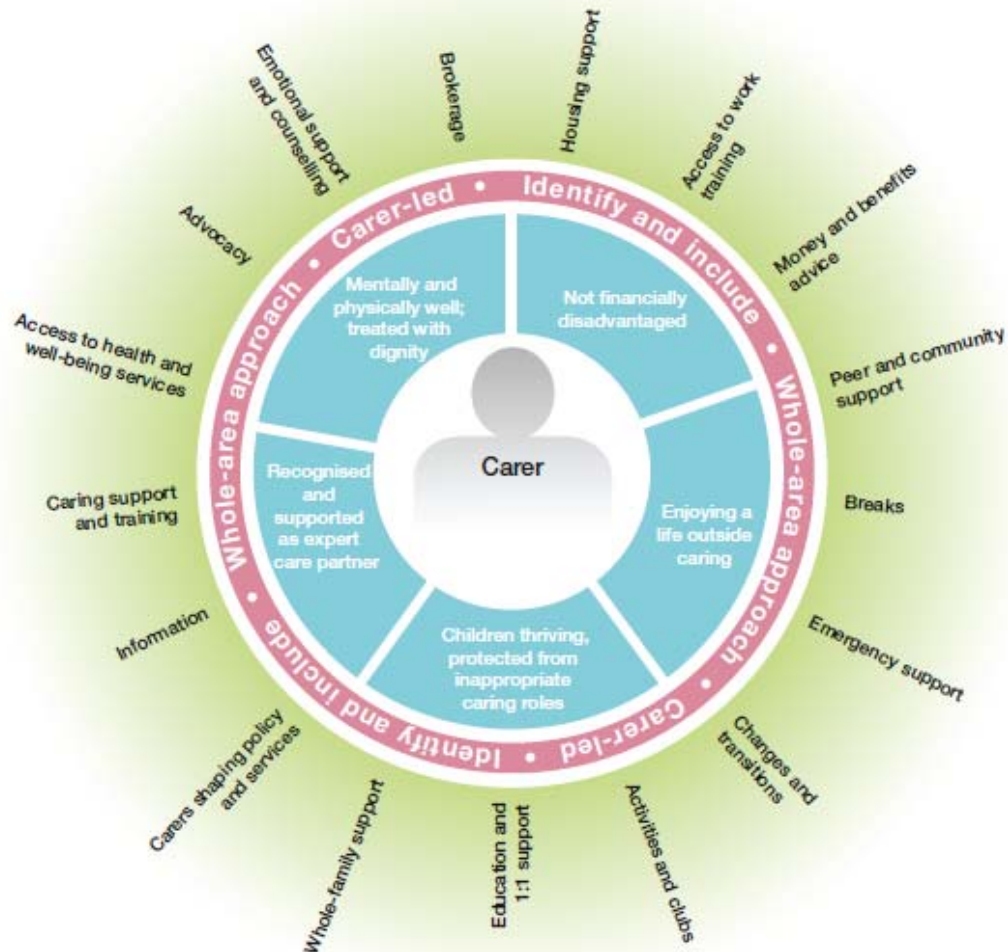
*NB it is important to remember that even those with complex needs will want to make use of many of the 'lower level' interventions.*

**Source:** Resource Pack “Making the strategic shift towards prevention and early intervention: Key messages for decision makers, Department of Health, October 2008.

## APPENDIX C

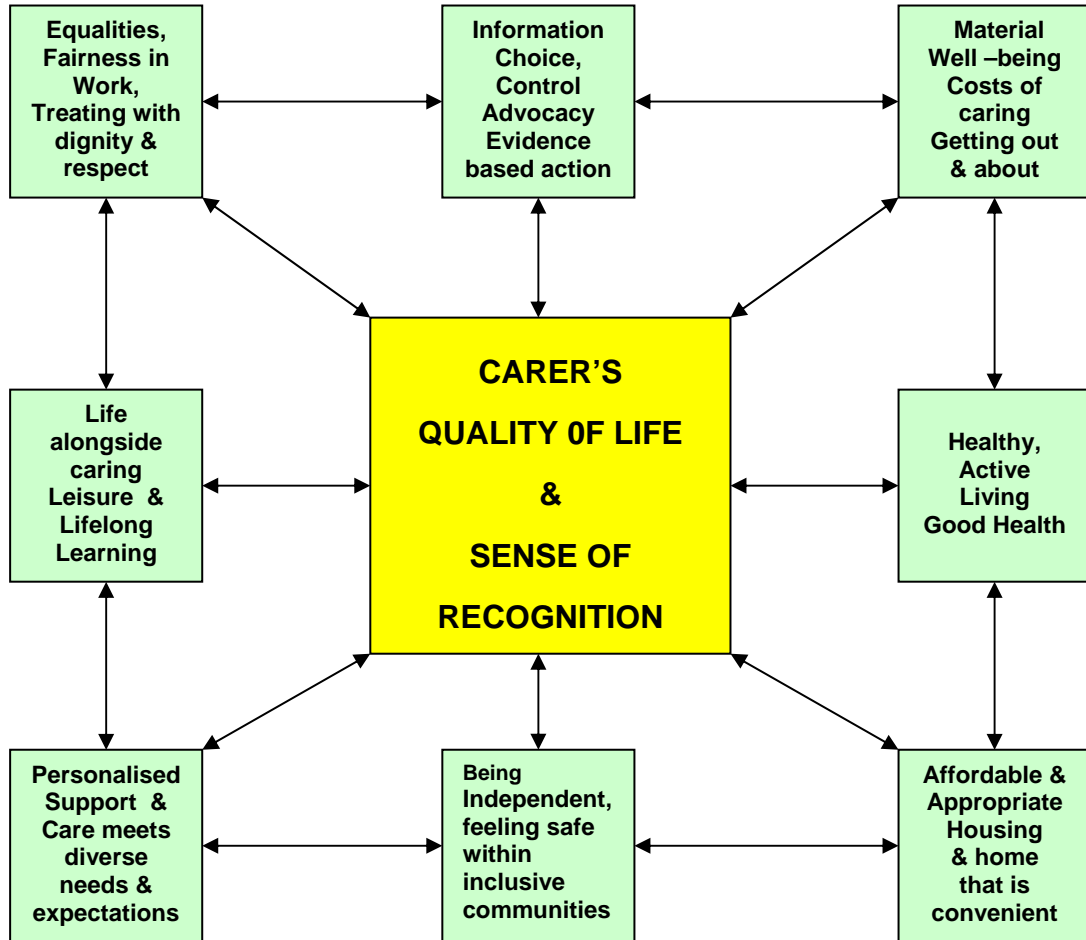
### A MODEL OF COMPREHENSIVE CARER SUPPORT MODEL [2009] [2]

Figure 2: A model of comprehensive carer support



**Source:** *Commissioning for Carers and Commissioning for Carers: An Action Guide for Decision Makers*, 2009. The Association of Directors of Adult Social Services, The NHS Confederation, The Local Government Association, The Improvement and Development Agency, The Princess Royal Trust for Carers, Crossroads Care, Carers UK and the National Black Carers and Carers Workers Network, with Department of Health support.  
[www.idea.gov.uk/idk/core/page.do?pageId=6001526](http://www.idea.gov.uk/idk/core/page.do?pageId=6001526),

**ASSOCIATION OF DIRECTORS OF ADULT SOCIAL SERVICES  
- A QUALITY OF LIFE MODEL FOR CARERS  
[For Discussion]**



**Source:** ADASS *Putting People First and Supporting Carers*, 2009[7]

[Adapted from: *The Future is Ours* [a], *A Sure Start to Later Life* [b] and *Opportunity Age* [c]]

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Published May 2010.  
Princess Royal Trust for Carers and Association of Directors of Social Services  
Printed by Warwickshire County Council  
Available in PDF format from:

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