

# Annual Statement

by

## Carers Together

### November 2007



**‘An effective Carers Strategy will reflect the views of carers, be flexible and acknowledge that it cannot be definitive but will point to a desirable focus for carers services and support’**

**‘Independent individual advocacy for carers is a key to good carers support’**

**Carers Together Annual Statement – August 2007**

**KEY STATEMENTS**

‘An effective Carers Strategy will reflect the views of carers, be flexible and acknowledge that it cannot be definitive but will point to a desirable focus for carers services and support’

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‘Independent individual single issue advocacy for carers is a key to good carers support. It ensures that carers have access to good information about their rights and appropriate support as and when they need it’

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‘Caring is not a paid occupation. It involves emotional and practical support between individuals who are all different’

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‘Caring is not an exact science because no carer is the same as another’

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‘There are several statements that can describe a carer because it is impossible to give a single overarching description that has real meaning for all the people in a caring role’

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‘Simply – all carers are different, caring for and about different people, who themselves are all individual’

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‘Carers support is not the prerogative of any one organisation’

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‘Carers Support can be ‘Direct’ or ‘Indirect’ or ‘Community’

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‘The situation is no different from 10 years ago, when carers were struggling for recognition, respect, support, respite and information’

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‘Services that give best value are constantly monitoring themselves and the situation around them’

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‘Carers need a range of solutions that fit key words such as choice, information, best value, added value, partnership, cooperation, coordination, flexibility, responsiveness’

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‘There is no simple solution, but there are some very clear pointers, that could lead to better carer satisfaction’

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‘The Government has issued a number of recent guidelines stating that carers support services must be seen to be independent and carer led’

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‘Services are only valued if they meet the individual needs of the carer’

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‘Some services are probably better supplied in-house by statutory organisations’  
‘Some services are better supplied outside statutory authorities’

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‘Carers Together provides flexible comprehensive and responsive carers support’

## **‘Independent individual advocacy for carers is a key to good carers support’**

### **Carers Together Annual Statement – August 2007**

(In this document the word ‘carer’ means an unpaid, informal relative, friend or neighbour to someone who is disabled, has a long term medical condition or illness or is an older person)

## **‘An effective Carers Strategy will reflect the views of carers, be flexible and acknowledge that it cannot be definitive but will point to a desirable focus for carers services and support’**

A strategy is a systematic plan, produced as result of a comprehensive consultation process, to identify the proposed future action and overall direction of an organisation, network or partnership. It should include a vision of excellence.

It is a written statement of what an organisation should be doing to achieve the objectives identified during the strategy consultation.

It should have no finite start or end dates, but should be constantly evolving in the light of ongoing experience, dialogue, feedback, consultation and change in government directives/legislation.

## ***‘Independent individual single issue advocacy for carers is a key to good carers support’***

Independent individual single issue advocacy ensures that carers have access to good independent support and information about their rights when they need it. It means they are supported each time to achieve the best outcome for them. Individual carers champions should be trained and experienced in ensuring that the carer’s views and wishes are understood and paramount

## ***‘Caring is not a paid occupation’***

It involves emotional and practical support between individuals who are all different

Caring is part of a personal relationship between two or more people who are emotionally bound by a mutual need or concern.

Our English word 'care' comes from an old English word. The verb means 'to feel concern or interest for', 'to provide food or attention for'. The noun is defined by the dictionary as 'solicitude, anxiety, heed, caution, pains, serious attention, charge, protection.'

Paid workers, who work with carers and the people they care for, are not carers. They are workers who support and work with carers and the people they care for.

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***‘Caring is not an exact science because no carer is the same as another’***

The way someone cares depends on a range of factors including: the person, their personality, the support they receive, the family they have, the friends who understand, the professionals linked to them, their GP network, the hospital nearest to them, the person they care for and their disability.

Any individual can be both carers and dependent at the same time or can move backward and forward between the roles.

In his/her lifetime a carer can readily interchange between dependency and caring. Everyone at some time becomes a dependent and everyone at some time becomes a carer, although many do not recognise the roles.

A parent may be caring for a child with a recognised disability. Although there may be other children with the same identified disability, every disabled person is an individual with some of the inherited genes of their parents and some of the inherited genes of the disability. They are all different individuals, even when in the same family, and their specific care needs are also different.

A parent may also be caring for his/her parent and have torn loyalties. One parent of a child with disabilities may develop a disability and become a parent carer who is also dependent on the other parent, a relative or friend. Computations and variations in caring are ever changing and endless.

***‘There are several statements that can describe a carer’***

- A carer is someone who, without remuneration, has the main responsibility for providing or for arranging care for someone else who, because of long-term illness, disability, or old age is not able to care for him or herself
- A carer is a person who gives support and assistance to a relative, friend or neighbour who has an illness or chronic condition
- A carer is anyone who provides or intends to provide a substantial amount of care on a regular basis.
- The word 'carer' refers to people who provide unpaid care to a relative, friend or neighbour who is in need of support because of mental or physical illness, old age or disability.

It does not include people who work as volunteers or paid carers; these people should be referred to as 'care workers'.

It is also important to remember that some people who use social services are also 'carers'. For example, many people with learning disabilities provide support to their ageing parents. (Social Care Institute for Excellence SCIE October 2005)

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- The term carer refers to anyone who cares for another person and is not paid for it. Caring duties can range from helping someone with the shopping to giving 24-hour care. (CSCI 2006)

It is impossible to create a single simple description of a typical carer because there is no average carer who could fit the mould. This dichotomy makes it difficult to create a carers support service, as a single separate individual service that meets carers needs. In no case is there a simple, single example of caring that can be called typical, but there is always a need for help, support, advocacy, counselling, friendship and understanding.

Carers come from every walk of life, from any career, and bring with them a wide range of skills and experience. Because they are all different, carers need a wide range of flexible support to help them to manage their own time effectively, and have a break from caring when, how/where needed.

### ***‘All carers are different, caring for and about different people, who themselves are all individual and different’***

There are as many different carers in the world as there are different people. Each person is an individual with their own needs, rights and responsibilities that belong to them. This does not change because they are a carer. Although they may have some common wishes, needs, or responsibilities each carer will approach them differently, so support will need to be appropriate for each individual.

### ***‘Carers Support is not the prerogative of any one organisation’***

Carers support is not the prerogative of any one organisation and it does not need to have ‘carer’ or ‘support’ in its title to provide excellent support services for carers.

Carers Support is often piecemeal, with different organisations/groups competing for limited funds to provide formal, recognised, carers support to meet different aspects of perceived carers needs.

No single authority or voluntary organisation can provide all services to meet all needs.

Until it is accepted that there is no typical carer with average needs and wishes, support for carers will continue to be less than satisfactory and authorities continue to fail to meet their duty to give appropriate individual Carers Support based on an assessment of individual need.

**‘Independent individual advocacy for carers is a key to good carers support’**

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***‘Carers Support can be ‘Direct’ or ‘Indirect’ or ‘Community’***

**Direct Carers Support** - is provided by an organisation, service or group set up specifically to give support to carers. This can be in a range of different formats, methods and services but will have the primary aim of supporting carers.

**Indirect Carers Support** - is provided by an organisation, service or group, statutory and/or voluntary, set up specifically to give support to people with a specific disability, medical condition or illness but which give considerable support to carers, deliberately or by default, because of the support they give to the person being cared-for and the networks and information they establish.

**Community Carers Support** - is provided by a wide range of organisations, services and groups, statutory and/or voluntary, that provide a range of community facilities that carers can tap into as and when needed. These will not be specifically for people with disabilities or carers but will be available to any citizen on a basis of need e.g. Voluntary Services, CAB, Red Cross etc.

***‘The situation is no different from 10 years ago, when carers were struggling for recognition, respect, support and information’***

The response by different authorities was piecemeal and, until the Government Carers Strategy in 1995, there was no identified acceptance of ‘Carer’ as a recognised role.

Some statutory authorities have a very good awareness of carers; most recognise the value of having a ‘carer’ for the person with an illness or disability; many provide a range of carers support based on historical demands and reports over the years. None of this is bad, and credit should not be taken from those authorities, which have moved forward on the lines of previous recommendations and reports.

However, it is now a time of reducing financial stability for authorities and voluntary organisations involved with carers. It is therefore a good time to re-examine the current levels and type of support and investigate if they are all giving best value.

***‘Services that give best value constantly monitor themselves and the situation around them’***

They need to be honest about what they provide and consult regularly on what is needed. They need to respond positively to changing needs and be open about what they can do and what others may better achieve.

It is important for organisations to look at their service provision and seek best value responses i.e. essential (challenge), needed or wanted (consult), desirable (compare), cost effective (compete).

One of the main problems for carers, and those that support them, is that very often the carer does not know what he/she really wants until they have been caring for while, and

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it is therefore with gratitude that they accept whatever is offered initially. In many cases, they are then so afraid that the service will be removed and they will be left with nothing, that they are frightened to complain, or say what they really want.

There are many examples of this and much is related to subjective factors e.g. carers may like or dislike the social worker, fear or love the home carer, hate or like the day centre, would prefer different times and days, need a break but feel they must accept the local residential home on offer when they would prefer to go away with the person they care for or have care in their own home.

Another problem is that local authorities have traditionally based their services around buildings and existing group services such as day centres, residential homes, carers centres etc. Having invested their money in these services, they feel that they have either met their obligations to carers, or must use the services to warrant the level of financial support needed to maintain the high cost, highly resourced buildings and centres.

Over many years the overhead costs of statutory and voluntary organisations have grown out of all proportion to services. Although these are often essential to enable them to meet their legal obligations, it is very difficult for an authority to separate the commissioning, monitoring role from the role of providing services and support. This also has an effect on their perceived failure in meeting the real and multi-varied needs of carers.

Change in service provision should reflect the majority needs and wishes of carers as well as the changing situation around them – they should be seen to be responding to the wishes of carers and not just to the current financial situation or statutory policy

***‘Carers need a range of solutions that fit key words such as choice, information, best value, added value, partnership, cooperation, coordination, flexibility, responsiveness’***

In order to achieve flexible and responsive solutions, it is essential to consult carers at every level and offer an individual, purpose built package of care on every occasion (Service Brokerage). The only way for this to be possible is for health, social services and the voluntary sector to give a real commitment to consultation with carers and to respond to the changing and evolving individual needs being identified.

In other words **challenge, compare, consult and compete** in an open forum.

Token consultation with one or two carers outnumbered by the people and groups that have a vested interest (whether in the status quo, or in increasing their own input), does not seem to meet the best value principle, or identify/meet the needs of individual carers.

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***‘There is no single simple solution, but there are some very clear pointers, that could lead to better carer satisfaction’***

Carers need to work with Social Services as well as a wide range of other statutory agencies such as Primary Care Trusts (PCTs), Hospital Trusts, Strategic Health Authorities, Patient Advice and Liaison Services (PALS), Patient and Public Involvement Forums, Patient Forums, Local Strategic Partnerships, District Councils and Education.

Statutory organisations and agencies are required to consult with people who use their services and this can put a tremendous consultation and/or representative burden on carers unless the different agencies work together with them to achieve cohesive, cost efficient and effective results. Sometimes the consultation is perceived by carers as ‘tokenistic’.

Joint working and pooled spending would achieve more than piecemeal action and would be less time consuming and achieve added value, especially if added to and coordinated with resources gained by local and countywide carers organisations from other sources.

There are many groups, organisations, public and private agencies already providing a wide range of ‘general’ services and support that carers are able to tap into. Authorities could enhance these by enabling the carers to access the particular service, support or activity that is wanted, needed or required by each individual carer.

Most carers want to live ‘as normally as possible’ within the caring role and may need

- support to manage their time
- a friend (or friends) in need to give the individual support required
- time out to do the things they enjoy, or try new things with other people who are not necessarily carers.

***‘The Government has issued a number of recent guidelines stating that carers support services must be seen to be independent and carer led’***

Instead of statutory/voluntary agencies trying to push through changes, or bringing in new organisations, is it better to work together to look at and help enhance what is already there? This is better use of funding and does not create operational competition, which can happen if there are two or more services providing direct carers support services in an area. Carers do not understand or want that and feel they are torn between them.

Why re-invent the wheel? What is the advantage of using public funds to set up two or more services in opposition? How can public authorities and departments warrant funding a carers’ service, which will then be in competition with a registered charity or constituted body already operating in an area, and which has accessed funds from other sources to enhance the service provision for carers? This includes national charities (e.g. MIND, SCOPE, MENCAP, RETHINK) as well as local charities (e.g. Wessex Cancer Care, Alzheimer’s, Carers Together, Carers Forums, local independent carer and user organisations/groups)

## **‘Independent individual advocacy for carers is a key to good carers support’**

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#### **‘Services are only valued if they meet the individual needs of the carer’**

- **Support groups**

Support groups may be one answer. Some carers want a support group, and need to know that there are other people with similar problems, that they are not alone and that it is ‘OK’ to be sad, angry, frustrated etc, but many express a preference for contact with other carers in different ways e.g. telephone, personal visits, email, internet. It is often impossible because of their caring role to meet on fixed days and at fixed times.

Carers Support Groups are often underused. Several carers have said ‘I go to the carers support group once month because I feel sorry for the person running it – she puts such a lot into it and very few people turn up so I feel I must’. Some find a carers support group invaluable, some prefer to go to specialist groups run by a range of organisations, some prefer general support. The variety of needs make it difficult to provide a standard carers support group and one that flexibly meets local carers needs is probably most beneficial.

- **Assessment of individual needs is essential**

This includes assessing needs and helping carers to find the right package of care for them, helping with finance issues for the carer and the person they care for, giving them the opportunity to take advice from independent Direct Payments workers and monitoring the ongoing needs and service provision. Single Assessment Process (SAP) should provide a better, more coordinated service for carers and the people for whom they care.

- **Information**

Information is necessary for carers and people who are disabled. The information they need is wide-ranging and provided by lots of different people and organisations. Many carers have expressed the need to have accurate information, up to date and available when they need it and where they need it. They want a comprehensive information service that they can access where they happen to be, not have to go from place to place to access it. This needs cooperation from all groups in each locality, to work together and provide accurate comprehensive information about the range of services in the local area for all the citizens e.g. Romsey Area Information Network (RAIN). It is a task being looked at by some District Councils as part of their Local Strategic Partnership.

- **Carers need an independent, non-judgemental, confidential listening ear.**

They need to know they can offload all their frustrations or just ring for a chat when things are getting them down. They need to know that the person on the telephone is independent and not from Health or Social Services, as otherwise they cannot express some of the frustrations they have with those services.

A ‘Listening Ear’ for carers is best provided outside the management of statutory bodies who need to run their own out of hours and emergency services as part of their own service provision. The carers support element should be seen to be separate at all times so the people staffing the service can advocate for them with the authorities if necessary. This service could also be provided more cost effectively by an independent organisation.

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- **Carers Networks**

Carers Networks are growing as carers realise that they can become part of a changing network of support, information, listening, advocacy and mutual interests. Networks can link carers through different channels of communication, training, signposting and information. They can include Carers Awareness Courses, activity ideas, first aid, advocacy, financial awareness, email, telephone, Internet, relaxation and personal contact. Carers Networks need to be flexible, developing and changing to meet the needs of individuals and should go out to where carers are rather than expect carers always to come in to a centre. Carers Networks can only be achieved outside the management of public authorities and are better based in an umbrella carers organisation, which is continually responsive to the changing needs of carers.

- **Sitting services**

Sitting services are a recognised support that is personal, and as far as possible, meets the times and days of the carers choice. However, many carers say they want to use this limited time to do shopping, or visit friends or do a leisure activity rather than meet with other carers or have their time arranged for them. Most sitting services offer fixed times and days which is helpful in planning time off but does not meet the need for emergency or surprise activity. This needs a more flexible approach to choice and respite care.

- **Respite care**

Respite care in the form of day care, sitting, cleaning, personal care and residential care can be made available as an in-house service or through effective commissioning, but respite care should not only consist of this small number of identified services.

Each individual will have a different idea of what respite means to them and service commissioners should be flexible to match the service provision to the carer’s needs not expect the carer to fit into the parameters of services they have established.

This will mean putting financial and other resources into an ever-changing supply of flexible and different community and respite services e.g. befriending. It may be difficult if not impossible for Social Services to maintain all their in-house respite and care services, which need high funding commitments. It is possible there will be a need to rationalise the level and supply of building based respite and to offer flexible and more effective services as a result.

### ***‘Some services are probably better supplied in-house by statutory organisations’***

These include commissioning in a wider sense; independent and unbiased information about residential, domiciliary and day service provision (already provided and available annually in Hampshire and much valued) and an input into assessment of individual need.

However, assessment of needs (carers or dependents) should not be undertaken by any organisation in isolation. It should be the result of multi-agency, multi disciplinary input with major input from the person themselves and their carer. Possible solutions need to be responsive to individual need and include a range of services that may have an input.

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Commissioning, information and assessment form part of the duty of care of statutory organisations and should be undertaken in partnership with others. Partnerships could be led by carers – it does not always have to be led by statutory organisations e.g. RAIN, RADISH.

Provision of services needs to be looked at individually and separately – however all services need to work together to provide a coordinated service that make best use of limited resources and gives a comprehensive, efficient, effective and professional service.

#### ***‘Some services are better supplied outside statutory authorities’***

Carers should be supported appropriately to the locality where people live, making use of the range of carers support already available, direct, indirect and community.

Duplicating services or creating complicated systems where more than one service is operating in an area cannot be seen to be cost or personnel effective. Nor does it provide a clear line of support for carers who are already struggling with the complicated procedures they have to go through in order to get any support at all.

Where there are gaps in provision, the development of services should be promoted to fill the gaps. This should not just be ‘named’ carers services, but a range and variety of services to meet individual needs whatever they are.

What do carers really want? Is it really being supplied or is it time to grasp the nettle and propose something different? Why change or continue with the status quo if rationalising or working together can achieve added value?

Some services are better led by carers. These include:

- Carers Support
- Carers Information
- A Carers Listening Service e.g. CALL, CLICK, CASS
- Carers Awareness
- Carers Training
- Carers Activities

These should all be led by ‘carers voice’ organisations in each natural locality but linked and supported by a county wide network to help share good practice, give administrative support and encourage equity.

To be really effective they need consistent funding and resources. Funding agreements are temporary or short term. Some service level agreements provide advice and support across the whole of Hampshire (excluding Southampton and Portsmouth). Others provide carers support in specific social services areas of the county. Some provide carers support in Southampton. There is no single organisation that can supply all the answers. Carers Together is one organisation that provides direct support to carers.

## **‘Independent individual advocacy for carers is a key to good carers support’**

### **Carers Together Annual Statement – August 2007**

#### ***‘Carers Together provides flexible and responsive carers support’***

The boundaries of Social Service and Health areas have changed at least three times in the last 15 years and Carers Together made the decision some time ago to undertake its work within its area of benefit and in natural localities.

As part of its aims and objectives Carers Together produces a countywide newsletter and welcome articles and input from other groups and organisations.

It regularly invites carers from across the whole county to be involved with consultations to ensure they have a voice in local, county and national issues.

Funding is received from a range of sources, health, social services, education and voluntary to provide particular, specific and general carers services in different areas and for different purposes.

Carers Together has always provided carers support to any carer in historic Hampshire and works with the wide range of services, groups and organisations that give support to carers both directly and indirectly in every area.

For many years it has had regular contact with every GP surgery in Hampshire and has recently, in consultation with several GP surgeries, developed a Carers Registration form and system, which has had a substantial and positive response.

Carers can access services already available in the community such as advocacy (very limited at present), counselling, sitting, cleaning, befriending, financial advice, leisure. Arranging for the carer (and funding it when necessary) to access existing services, helps prevent the need to set up specialist services for carers that are often underused.

There is considerable value in having an independent umbrella organisation to support and maintain some equity across the wider county area, working side by side with local Carers Forums based on

local natural localities rather than artificial areas created (by health, social services, education and other statutory bodies) solely for dividing population numbers.

Independent Carers Forums have the added benefit whereby they can apply to others sources for funding and work together with other groups in the locality to make best use of people and resources in the vicinity (Service Brokerage). They should be carer led and carer managed with the ability to employ their own staff and develop to meet the changing needs of carers in the locality rather than be tied to buildings and services, which are being provided ‘for carers rather than with carers’. (e.g. Romsey and District Carers Forum; New Forest Carers Forum; Carers Together Southampton).

Encouraging independent Carers Forums in each natural locality, linked and affiliated to the county wide organisation, could save money, enable other funding resources to be accessed, provide a better service, stop confusion, encourage partnership working in each locality, produce accurate and comprehensive information for local citizens whichever role they find themselves in at any given time, and ensure that best use is made of limited resources.

**‘Independent individual advocacy for carers is a key to good carers support’**

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Carers Together issues the Annual Statement each year to reflect the views of carers expressed during the previous and earlier years.

It is not a definitive statement but represents the continuing awareness and development of carers needs.

The Annual Statement was first issued in 2002 by Carers Together in Hampshire

The statements have all been made by carers during the last 15 years

This annual statement it is updated regularly in response to the changing situation for carers.

**For copies please contact:**

**Carers Together  
9 Love Lane  
Romsey  
Hampshire  
SO51 8DE**

**Telephone: 01794 519495**

**Fax: 01794 519895**

**Email [admin@carerstgether.org.uk](mailto:admin@carerstgether.org.uk)**

**Website: [www.carerstgether.org.uk](http://www.carerstgether.org.uk)**



**Carers Together is constituted to include Hampshire Portsmouth and Southampton**

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A possible mapping plan for Carers Support is shown below.



**Green - Carers action**

**Blue - Actions by Carers Together & Carers Forums**

**Red - Social Services Actions**

**Black - Actions by social services or other organisations**