

DRAFT

Kent Adult Carers' Strategy



Acknowledgements:

Many thanks to the editorial group:














Priscilla McBean – Carer
Ron Alexander – Carer First
Sheila Pitt – NHS Eastern and Coastal Kent
Linda Caldwell - NHS Eastern and Coastal Kent
Julie Van Ruyckevelt – NHS West Kent
Emma Hanson – Kent Adult Social Services

Particularly thanks to

Carers from the Maidstone Carers Project and the Swale
Carers Men’s and Women’s Groups for their poignant quotes
used throughout.

Contents

DRAFT

	Forward	3
	Importance of supporting carers	8
	Who is a carer?	14
	What do carers do?	16
	Carers advisory group	18
	The National Carers Strategy	20
	Information, advice and guidance	22
	Access to integrated and personalised services	24
	Having a life of their own	26
	Carers are not forced into financial hardship	28
	Staying mentally and physically well	30
	Carers having a voice	33
	Delivering the strategy	35



Forward

This strategy sets out the vision we plan to take forward, working in partnership across Kent. We will build on the progress established via the carers grant funding and use the framework set out in the National Carers Strategy. In Kent we have committed to deliver the national strategy in five not the suggested ten years. This sets us a tough but we think achievable target that requires multiple levels and types of partnership work and co-operation across health social care and the private and voluntary sector. It will involve forging new partnerships with employers, education establishments and the job centre plus.

There are many reasons why people take on the caring role. People who care do so because they want to; they care out of love and duty. Care and caring are important factors in community life and one of the foundations of a strong and sustainable society. Nevertheless the role can be a demanding one and one that often people are ill prepared for.

Society is changing, as a nation our life expectancy has improved and we can all expect to live longer, which is a good thing. In direct connection the chances of becoming a carer are increasing all the time, everyone has the potential to become a carer, and it is likely that in the future more and more of us will have some caring responsibilities.

Every year 2 million people move in and out of caring relationships, carers are not a static group and every day approximately 6,000 people take on new caring roles, this presents a real challenge in providing information, advice and guidance to support those new to caring and inform them of their rights and the services and support that is available to them.

Too often carers are forced to ignore their own needs because of the demands they are under. Across Kent, we have made a commitment to work together to ensure that taking on a vital caring role does not mean people having to take less care of their own health or career opportunities or suffer from social exclusion. We believe that carers are entitled to their own lives and are important in their own right as individuals not just for the role they provide. Increasingly carers are coming out of the shadows and are becoming more and more visible as part of the wider community and rightly so. There is a growing recognition of the importance of carers' rights and entitlements. This strategy is a clear commitment from all the organisations, both public and voluntary that have a role in working with and support carers in the Kent County Council area.

Central to the development of this strategy and the general approach towards the carers in Kent is the principal that carers are the main providers of community care who should be supported in their role. We do not underestimate carers' contribution to society, if carers were to give up providing the care and support they offer it would be akin to losing the whole of the NHS.



Caring can be demanding and rewarding, sometimes people need and are entitled to specific services such as short breaks and emergency or crisis support services. Taking on a caring role often means people juggling the support they give with other responsibilities, combining caring with work, getting access to training or simply having time to take a break and go away for a weekend can be a major challenge. The services and support that we design in the future must be flexible and able to adapt to meet the needs of a wide range of people; therefore delivering greater levels of choice and control to carers will be a priority.

We must lead the way in developing carer friendly employment practice, creating flexible working conditions that allow carers to remain employed whilst caring for family

or friends. Carers have often told us that not only is work a source of income but it is a great form of respite, and also helps with the emotional wellbeing of people. We will be working with Job Centre Plus to ensure carers who have been out of the job market are supported to retrain and gain skills and confidence to re enter the work place.

No strategy sits in isolation, a major challenge in delivering the aims of this strategy will be to ensure coherence with work being undertaken in Kent to deliver other key local and government strategies, such as the Young Carers Strategy called 'Invisible People', 'Living Well with Dementia' the National Dementia Strategy, the End of Life Care Strategy and the Stroke Strategy. All of these strategies have acknowledged and placed a high regard upon ensuring that needs and wishes of carers are foremost in planning new models of service and support.

Fundamental to the success of delivering this strategy is the full recognition of the role and contribution that carers make. In the past year we have made significant progress in developing a more inclusive and coherent approach to meeting carers needs. We want to maintain that open dialogue to ensure that we can draw on carers expertise and involve them at every stage of planning, commissioning and quality assuring services and support.

This strategy contains high level objectives that will be supported by more detailed delivery plans, one in the east and one in the west Kent, coterminous with the relevant NHS organisations in each area. In forming these plans we will consult with carers and the organisations that support them.

LOGOS

Importance of Supporting Carers

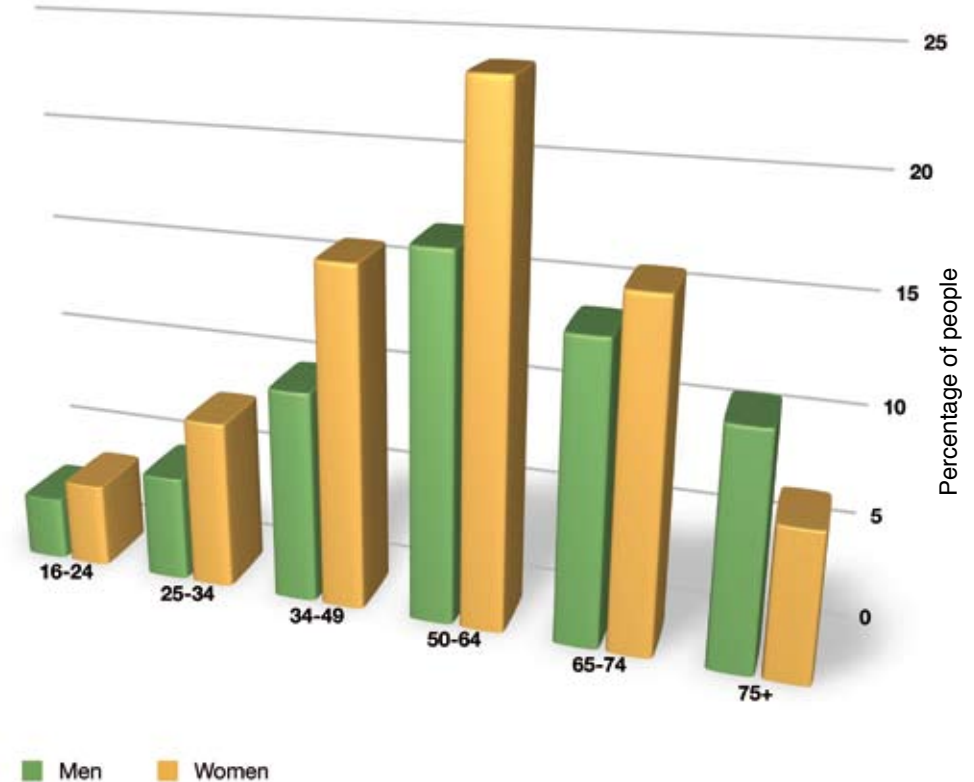


The way that carers are supported is crucially important and will be increasingly so in the future. Current estimations show that one in ten people in the UK is a carer; the percentage in Kent is even higher. In Kent on average 12.58% and in Thanet 14%. Society's structure is changing, we have a rapidly ageing population. By 2020 the number of people aged over 65 is set to increase by almost a third, the over 85s are set to double and over 100s quadruple. At the same time the average man will have nine years living with long term limiting illness. All of these changes will create additional pressures for health and social services but will also mean that in the future many more people will have to take on a caring role and for longer periods of time.

Kent Carers Facts and Figures

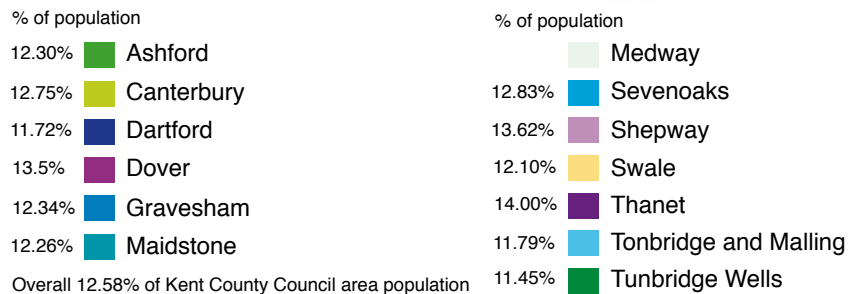
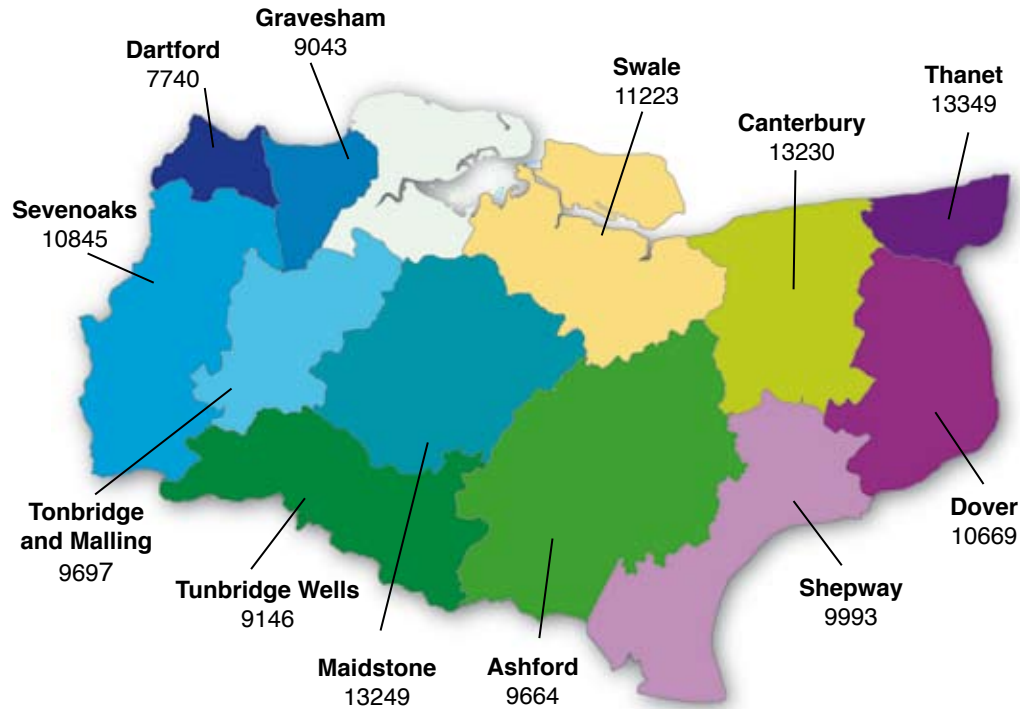
Key figures for carers in Kent are taken from the 2001 Census and General Household Survey 2000;

- There are **127,848** carers in Kent;
- **90,752** carers are providing care for 1 – 19 hours per week;
- **11,893** carers are caring for 20 – 49 hours per week;
- **25,203** carers are providing care for 50+ hours per week;



25,203 of Kent's carers provide more than 50 hours of care per week. Although caring has historically been viewed as a predominantly female role. **Table 1** above shows that in later life, more men aged 75 and over are carers than women.

Number of carers (2001 Census)

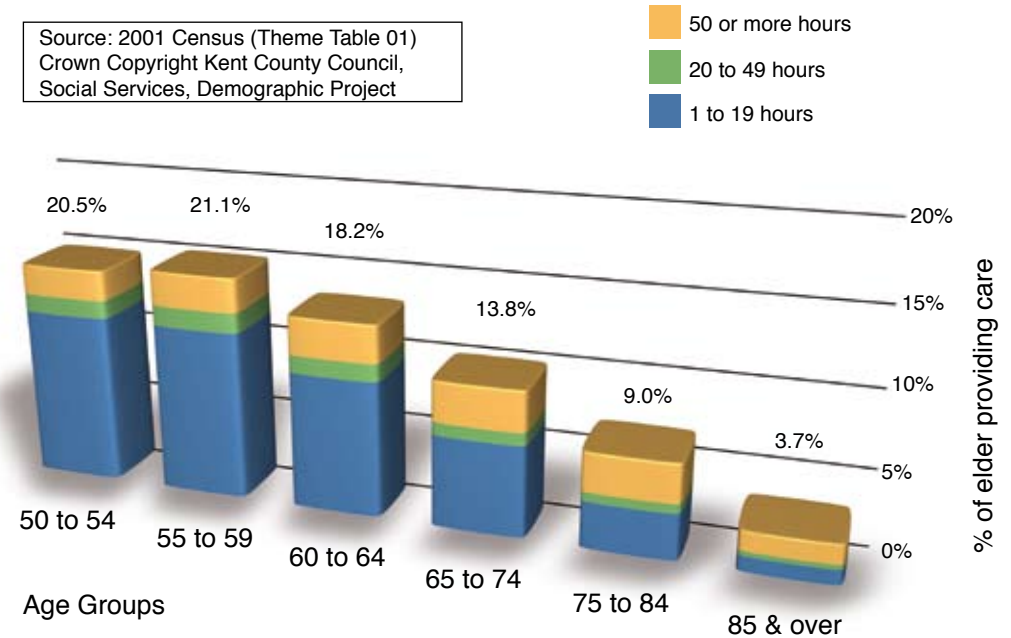


Produced by Performance Monitoring Team, Kent Adult Social Services
 This map is based upon Ordnance Survey material with the permission of the Ordnance Survey on behalf of the Controller of Her Majesty's Stationary Office
 Crown Copyright. Unauthorised reproduction infringes Crown Copyright and may lead to prosecution or civil proceedings. 100019238. 2007

This map shows the numbers of carers per Kent District or Borough, as recorded in the 2001 Census.

Table 2 shows that although the majority of carers are aged under 74, when you reach older age, 75 years plus you are statistically more likely to be providing higher levels of care.

Older Carers (aged 50 and Over) KCC Area



A Carers UK Study in 2004 showed that nearly 21 per cent of carers providing more than 50 hours of care report that they are not in good health, compared with only 11 per cent of the non-carer population. People who provide long hours of care are twice as likely to be in poor health themselves, and need to be supported both in their own right and in their role as carers.

The study also found that carers were more likely to report high levels of psychological distress, including anxiety, depression, loss of confidence and self-esteem, than non-

carers. Stress experienced can be the result of being on call for long periods of the day and seeing no end to the caring role, and may lead to the deterioration of relationships. Stress may mean that carers neglect their own health, for example by not eating properly, or they may neglect, or even mistreat the person they are caring for.

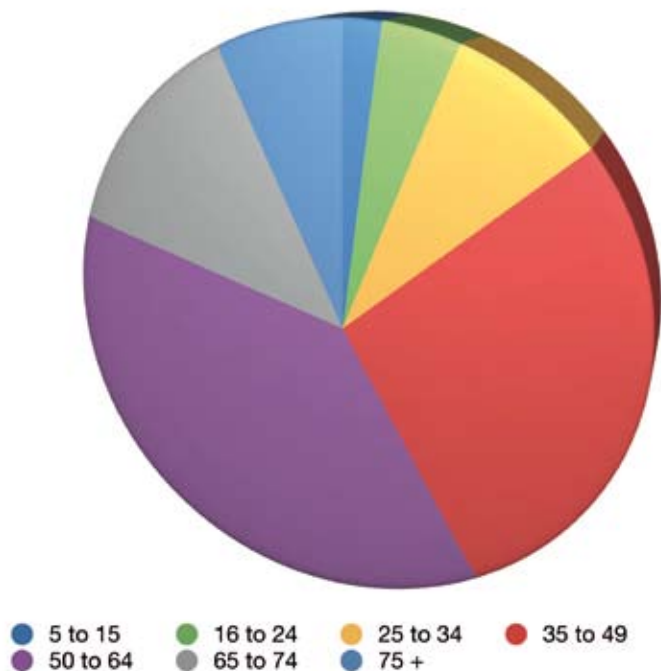


Table 3 shows the age breakdown of Kent's carers. Of the **127,848** carers in Kent, **78%** or almost **100,000** are of working age. Some will have given up work to care but the majority will be somehow combining caring with paid work. According to the 2001 Census there are **2564** men and **1394** women working full time whilst caring for more than **50** hours per week. In 2006 a Carers UK study found that working

carers pay a heavy penalty in terms of their own health. Those with heavy caring responsibilities are two to three times more likely than workers without caring responsibilities to be in poor health.

A 2007 Carers Employment and Services study commissioned by Carers UK from the University of Leeds showed that caring was strongly associated with poverty and that;

- 40% of full-time carers would prefer to be working
- Those who give up work to care most are the most disadvantaged and dissatisfied
- Many working only part time in low paid jobs because of caring roles
- Three quarters of carers say services are not designed and delivered in ways which enable them to work

Carers are not a static group, many grow into a caring role as their relative or friend becomes increasingly dependent, others become carers overnight as a result of accident or sudden illness. Annually more than 2 million people move in and out of caring situations. This creates logistic difficulties as the caring population is constantly changing, it places added value on getting the timely and accurate advice information and guidance to people.

Who is a carer?

A carer is someone who in an unpaid capacity provides care or support to another person. Many people do not class themselves as carers: they are mums and dads, husbands, wives, partners, brothers, sisters, friends and neighbours. Carers come from all walks of life, ages, ethnicities and backgrounds; they are not a separate group of other people. Throughout our lives most of us will either be a carer or be cared for.

Caring is a natural part of family and community life and informal unpaid carers have an essential role in society providing the majority of all community care. Health or social services could never replace the costs and the special values of the care they provide, which includes personal and emotional support, nursing, treatment and 24-hour supervision.

Anyone may become a carer and many of us will move in and out of caring roles during our lifetimes. Sometimes a caring role can be taken on unexpectedly following the sudden illness or accident of a relative. There are carers in every community and many juggle their caring role with paid employment. Some care for more than one person and many are themselves older, frail, sick or disabled.

Parent Carers

A parent carer is a parent or guardian who is likely to provide more support because their child is unwell or has a disability. Parents will often see themselves only as a parent rather than a carer.

Young Carers

A young carer is a child or young person (under age 18) who is carrying out significant caring tasks and assuming a level of responsibility for another person, which would usually be taken by an adult.

There is a separate Young Carers Strategy, which was named '**Invisible People**' by young carers across Kent. It should be read in conjunction with the Kent Adult Carers Strategy. Invisible People aims to raise awareness of the existence of young carers, promote the early identification of their needs and seek multi-agency responses to improve the outcomes for this group of young people and their families.



What do Carers do?



Carers help the people they care for to deal with and manage problems caused by illness or disability by providing physical, practical and emotional support to the cared for person.

Caring tasks can include providing intimate physical care such as helping someone get up, washed and dressed.

Often carers can carry out a great deal of lifting or assist with mobility. This may involve helping to change soiled clothes or bedding many times throughout the day and night.

Many carers undertake nursing tasks: they manage and administer medication, feeding tubes, colostomy or catheter bags or other medical equipment.

Carers of people with mental health or substance misuse problems may perform few physical tasks, but provide a great deal of emotional support, including helping to ensure that someone stays safe and responding to incidents of self harm or overdose.

The health impacts of this constant responsibility can be just as great as the impact of heavy physical caring. For some, caring can be an all consuming job leaving the carer physically and emotionally drained.

Caring responsibilities may be for short periods of time or in many cases, for a lifetime. The condition of the cared for person may change on a daily basis making it difficult to predict the demands on the carer.

Carers may be called upon to supervise someone to keep them safe and may do this from a distance.

Carers often take responsibility in supporting the person they care for to access statutory services, liaising on their behalf with organisations such as social services, health, education, housing, benefits, etc

Carers Advisory Group



The joint working and development of ideas that make positive contribution to the lives of Kent's Carers is essential now and in the future. To oversee the strategic development of the support offered to carers in Kent a long-standing **Carers Advisory Group** has been established. One of the first tasks of this group was to develop this Kent Adult Carers Strategy.

The Carers Advisory Group, which is facilitated by Kent Adult Social Services, includes representatives from all key partners involved in the support of carers across Kent. Membership includes policy makers and commissioner from Kent Adult Social Services, Children, Families and Education, Mental Health Commissioners, Carers' Support Organisations, the local NHS for West Kent and Eastern and Coastal Kent, the Job Centre Plus and other statutory and voluntary partners.

The role of the group is to focus on partnerships and joint working to develop a locally agreed response to current and future carers needs. The Group's work informs the planning and commissioning of services for adult carers across Kent.

The group's broad aims are:

- To represent the voice of carers and maintain awareness of carers needs and issues
- To seek the appropriate involvement and contribution of carers support organisations in the decision making processes and input into strategy and policy development
- To contribute to identifying priorities and inform the commissioning of new services
- To be kept informed of progress including the personalisation agenda and other practice and policy initiatives relevant to carers.

Carers Reference Group

To support and inform the Carers Advisory Group a Carers Reference Group has been established. This group is fluid in its constitution and is made up of carers from across Kent. A member of the Carers Reference Group sits on the Carers Advisory Group to ensure the needs and wishes of carers are represented and discussed.

If you are a carer and would like to join the carers reference group please call Kent Adult Social Services on 01622 696611 or alternatively send an email to kentcarers@kent.gov.uk

The National Carers Strategy



In June 2008 the Department of Health published a National Carers Strategy called: *Carers at the heart of 21st-century families and communities - "A caring system on your side. A life of your own."* The new National Strategy is seeking to respond to the needs of carers within the context of social and demographic changes. The intention is that over the next ten years the needs of carers have to be:

"... elevated to the centre of family policy and receive the recognition and status they deserve."

The National Strategy principals have been very well received in Kent. An agreement has been reached by the organisations within Kent responsible for supporting carers to aim to deliver the recommendations of the strategy within five years, not the suggested ten. The vision of this strategy and therefore the vision for carers in Kent is that:

"... 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 Kent Adult Carers Strategy is set out in the following five sections;

- Advice, Information & Guidance
- Access to Integrated and Personalised Services
- Having a Life of Their Own
- Carers not forced into Financial Hardship
- Staying Mentally and Physically Well

The first section Advice, Information and Guidance is not a distinct section of the national carers' strategy, however Carers in Kent have repeatedly told us about its importance and therefore we have chosen to include this as a separate section.

Information, Advice and Guidance



Our vision is that:

Kent carers have access to relevant and timely information to enable them to make informed decisions and choices about the support they offer to the person/or people they care for.

To be able to make informed choices about the most appropriate support or services, carers need to know:

- What is available and how to access it
- Whether they or the person they care for is eligible
- Who is providing it
- What to expect
- Any potential costs or charges, and
- Who to contact with queries, concerns or complaints.

What Kent carers say;

- It is important to tell new carers what help is available and where they can get help
- Knowing my rights and services etc would be very useful
- It took me so long to find the right information, but on finding it I felt that half the battle was over
- There is too much irrelevant information and it is difficult to work your way through to get the information that you really need.

How we will deliver this vision in Kent;

- Work together to make sure information is, timely, kept up to date, relevant, accessible and consistent
- Ensure information is available in a variety of formats, leaflets, fact sheets, websites, CD ROM's etc
- Support carers with additional communication needs and ensure information reaches seldom heard from communities
- Ensure information is easy to understand by using plain English and removing all jargon
- Ensure that information is available in the places that carers visit, supermarkets, shopping centres, libraries etc
- Ensure that information for carers is sensitive to the concerns and anxieties they face.

Access to Integrated and personalised services



The National Carers' Strategy Vision is that:

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.

What Kent carers say;

- Carers need to be on an equal footing with the professionals and the professionals should respect all carers
- Some professionals' assume they know best. I have shared my husband's life for 42 years and I know the things that are important to him
- I have been told that I don't know how to care for my wife, even though I have been doing it for the last 13 years. Go figure!

Many carers said that it was important for professionals to have a greater understanding about the role that carers have, and that we should ensure that carers' circumstances and needs are taken into account when they receive services.

How we will deliver this vision in Kent;

- Ensure carers are recognised as partners in care and that assumptions are not made about their willingness to care
- Carers are fully involved in the assessment and decisions of the person they care for
- Increase the number of Carers Assessments offered and completed
- Provide carer awareness and assessment training for all professionals
- Promote information sharing across Health & Social Care
- Extend the range and quality of services available to meet carers needs
- Improve carers access to health and social care support
- Develop plans to ensure that carers have the skills and information necessary to care with confidence
- Invest in strategies to engage with seldom heard from groups and black, Asian and minority ethnic communities
- Promote cultures that recognise the emotional needs of carers, during and after caring.

Having a life of their own



The National Vision is that:

Carers will be able to have a life of their own alongside their caring role

What Kent carers say;

The provision of breaks and replacement care are constantly listed as one of the highest priority by Kent carers.

- There are so few respite places in our area. It would be nice to have a choice
- Carers need more help than they are getting. This will enable the carer to have 'time out' from their caring roles
- Carers are not supported in their caring role, and feel really isolated and are unable to have a life outside of caring

When a person becomes a carer they give up many of the opportunities that non-carers take for granted. Carers' lives also become increasingly synonymous with the person they care for, which limits the opportunities they have for a life outside their caring role.

How we will deliver this vision in Kent;

- Ensure carers are recognised as partners in care and that assumptions are not made about their willingness to care
- Improve the range and availability of short 'respite' breaks and ensure they are provided in a flexible way
- Provide support to help carers recognise their own needs
- Ensure that assessment processes and services take account of carers' needs in relation to work and training
- Promote leisure, education and social opportunities for carers and other services which promote their social inclusion
- Provide services that can respond to emergencies
- Promote the Kent Carers Emergency Card
- Work to reduce the inequalities experienced by carers and especially those from hard to reach groups or communities.

Carers are not forced in financial hardship



The National Strategy vision is that:

Carers will be supported so that they are not forced into financial hardship by their caring role

What Kent carers say;

Improving the financial position of carers was noted as an important consideration by participants during the national carers strategy consultation. There was broad support for targeting financial benefits to those carers in the greatest need, in particular those who provide the most hours of care and those with the greatest financial hardship.

- Most of the carers allowance is taken away due to the fact that I'm not working although caring for my wife is a full time job
- Carers need more support to work without affecting their benefits
- When I decided to give up work to care for my mother I didn't realise that I would be choosing poverty.

Carers also want the opportunity to be able to combine paid employment with their caring role, which would both improve the financial position they are in and increase their opportunity to have a life outside caring. "It is difficult to work [carers] do not have the flexibility to work late, etc"

How we will deliver this vision in Kent;

- Promote benefit and income maximisation, including access to financial planning
- Produce an employers 'Carers Good Practice' guide
- To promote within Kent County Council, the local NHS and other employers the development of policies and practices which support carers to remain in employment
- Work with Job Centre Plus to develop schemes to aid carers back into employment, such as assisting carers to retrain to gain confidence and employment skills

We will also try to influence the Government regarding national issues such as Carers Benefit entitlements and flexible and supportive employment policies and practices.

Staying mentally and physically well

The National Carers Strategy Vision is;

Carers will be supported to stay mentally and physically well and treated with dignity

What Kent carers say;

- My consultant said that I need to go for a short walk every day – but I can't leave my husband alone and I'm not strong enough to push his wheelchair (carer with a heart problem)
- Carers often keep things to themselves and won't ask for any help
- I myself have been prescribed medication for depression and stress, but nothing about my physical welfare has been mentioned
- My GP has a register of carers within the practice. My GP understands my needs as a carer

How we will deliver this vision in Kent;

- Increase the range and quantity of short 'respite' breaks
- Improving mechanisms for identifying carers, for example by developing a GP Carers Register
- Ensure that professionals always consider carer's health needs
- Encourage professionals to recognise carers as partners and not make assumptions about their willingness or ability to provide care
- Ensure that Hospital Discharge planning procedures include discussions with carers concerns, needs and requirements
- Develop services that offer support and planning for life after caring
- Develop plans that ensure that carers have the skills and information necessary to care with confidence
- Promote leisure, education and social opportunities and other services which promote their social inclusion
- Ensure carers have access to psychological and emotional support when required
- Improve the availability and access to information, advice and training to support carers to fulfil their chosen caring role.



Carers having a voice

In delivering this Adult Carers Strategy all partners have committed to ensure that carers have a voice and will:

- Involve carers in planning, commissioning and evaluating services
- Work to include carers from hard to reach groups
- Involve carers in training professionals
- Involve carers in recruitment processes
- Include carers in our plans to raise awareness and deliver our strategies
- Explore engagement techniques that capture the views of carers who do not wish to attend meetings
- Work through existing carers support groups in the voluntary sector



Delivering the Strategy

The Kent Adult Carers Strategy will have two separate delivery or commissioning plans, which will be developed one for east and one for west Kent. These plans will show in greater detail how the strategy will be implemented.

Once developed plans will need to be regularly reviewed to ensure the strategy is meeting the needs of Kent's Carers.

DRAFT

Produced by Kent Adult Social Services
3rd Floor
123/135 Week Street
Maidstone
Kent
ME14 1RF

Tel: 08458 247 247

Photographs courtesy of Fotalia except page 32 courtesy
of Care Images