

# **CALDERDALE CARERS STRATEGY**

## **2012 - 2015**

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## FOREWORD

We recognise the vital role that carers play in our communities, and are committed to supporting them in that role.

This strategy has been developed by a group of local voluntary and statutory organisations. It sets out the progress that has been made in supporting carers over the last three years and identifies priorities for the next three. These include identifying more carers, supporting them and working in partnership with them to plan and deliver services, offering personalised support, providing support for carers to stay physically and mentally well, providing support for carers who want to work or continue to work and protecting, supporting and developing young carers. These priorities are based on common needs identified through ongoing discussions with carers and local organisations, and on national legislation.

The strategy is supported by a detailed plan setting out actions to address the priorities. We will monitor progress against this plan to ensure that we deliver the services and support that carers need and deserve.



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Clinical Chair  
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## INTRODUCTION

Here is the Calderdale Carers Strategy for 2012 to 2015. It has been produced by the Carers Strategy Group which consists of carers and representatives from the local authority, PCT/CCG, SWYPFT, Calderdale Carers Project and voluntary sector organisations that support carers. Carers Support Groups, Stakeholders and the Scrutiny Committee were consulted on the draft strategy and their feedback was used to shape the final document.

The strategy contains information about what has been achieved for carers in Calderdale in the last three years and what we aim to achieve in the next three years.

Carers can be friends, relatives, partners or neighbours. They can be young or old. They may have a paid or voluntary job or be in education as well as their caring role. They could be caring for someone with long-term physical or mental health needs, physical or learning disabilities, sensory impairment or drug or alcohol issues. They can live with the person they care for or not. They may be caring for more than one person, and they may have health problems or disabilities themselves.

Whilst carers can vary considerably, carers often have common needs which we aim to meet:

- They need access to up-to-date information about support and services available to them and the person they care for.
- They need support to maintain their own physical and mental health.
- They need flexible services to fit in with their lifestyle.
- They need a life of their own away from their caring role.
- They need the chance to continue working to prevent loss of income.
- They need to have the opportunity to maintain their social and family networks to prevent social isolation.
- Young carers need support to ensure their education, and therefore their future, does not suffer as a result of their caring role.

## **OUR VISION FOR CARERS IN CALDERDALE**

- Carers who are in need of support are identified including hidden carers and those from diverse communities.
- Carers are supported, their role is valued and their expertise is recognised.
- Carers are included as partners in the planning and delivery of services.
- Carers and the people they care for are offered personalised support, which enables them to be involved in their community.
- Carers are supported to stay well both physically and mentally, and are offered breaks.
- Carers who are working or who wish to work are supported.
- Children and young people are protected from inappropriate caring which ensures that they have the support they need to learn, develop and thrive to achieve positive childhoods and to achieve against all Every Child Matters outcomes.

## NATIONAL AND LOCAL BACKGROUND

### NATIONAL CARERS STRATEGY

“Recognised, valued and supported: next steps for the Carers Strategy”, the refreshed national carers strategy was published in November 2010 following a call for views on priorities for carers. It identified four priority areas for carers:

- Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages.
- Enabling those with caring responsibilities to fulfil their educational and employment potential.
- Personalised support both for carers and those they support, enabling them to have a family and community life.
- Supporting carers to remain mentally and physically well.

The strategy also included the evidence base for supporting carers, particularly working carers.

“Supporting Carers: The Case for Change” was published by The Princess Royal Trust for Carers and Crossroads Care in 2011 and developed the evidence base, emphasising the economic case for supporting carers.

It provided evidence that *“increasing support for carers:*

- *Improves health and wellbeing outcomes for patients and recipients of care;*
- *Improves health and wellbeing outcomes for carers, who suffer disproportionately high levels of ill-health;*
- *Reduces unwanted admissions, readmissions and delayed discharges in hospital settings;*
- *Reduces unwanted residential care admissions and length of stays.”*

In Calderdale, we know from local statistics that approximately 30% of admissions to respite care are to provide emergency respite for carers. The other 70% is planned respite care for carers' benefit. Local figures also show that carer stress is stated as one of the reasons why people are admitted to 24 hour care in 41% of cases.

Carers UK and the University of Leeds estimate that unpaid carers save the government £119 billion a year - this far outstrips the total cost of the NHS which is £98.8 billion a year.

## **CARERS IN CALDERDALE**

### **Census 2011 Statistics**

*The statistics from the 2011 census are not yet available – they will be added in when received, and the strategy reviewed to ensure it addresses the implications of that data.*

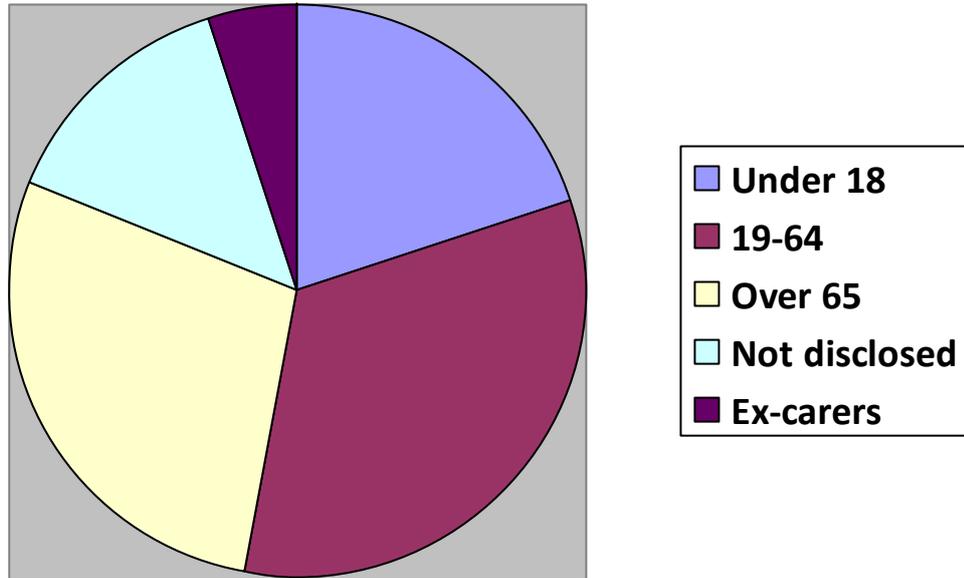
### **Calderdale Carers Project Database**

The Carers Project holds a database of carers registered with them. This is the most comprehensive source of data held on carers in Calderdale.

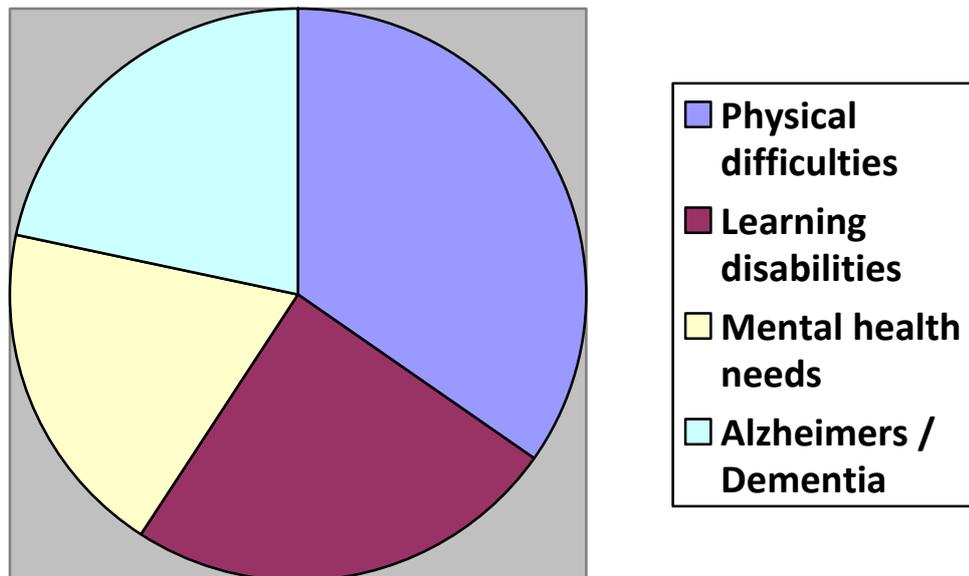
There are 1,722 carers and 89 ex-carers on the database making a total of 1,811. This is a large increase on the total of 1,022 carers quoted in the last carers strategy (April 2008 figures). As carers come and go, up to 1,000 new carers have joined the Carers Project over the last 3 years. This has led to increased pressure on the staff.

16% of carers registered are from Black Minority and Ethnic communities, compared to 7% in the last carers strategy.

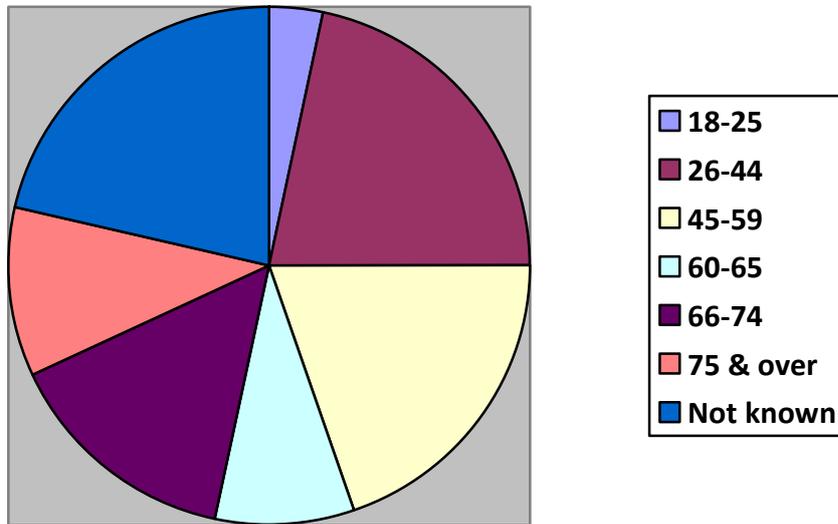
**Chart 2 - The age of people cared for (Carers Project Database)**



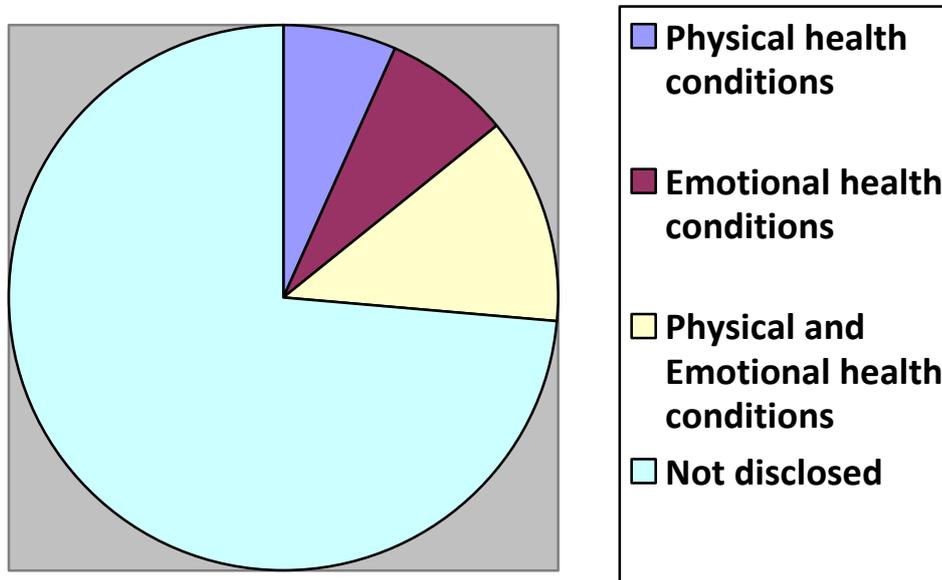
**Chart 3 – Condition of people cared for (Carers Project Database)**



**Chart 4 – Carers’ Ages (Carers Project Database)**



**Chart 5 - Health Status of Carers (Carers Project Database)**

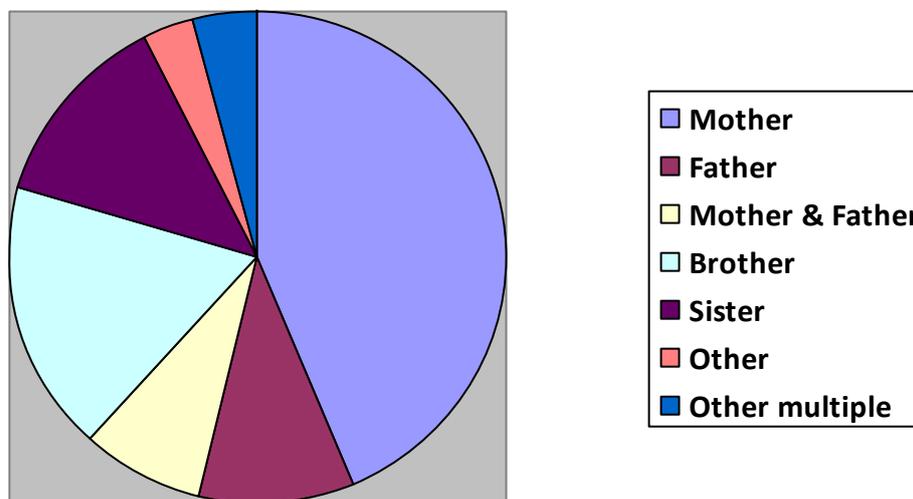


## YOUNG CARERS

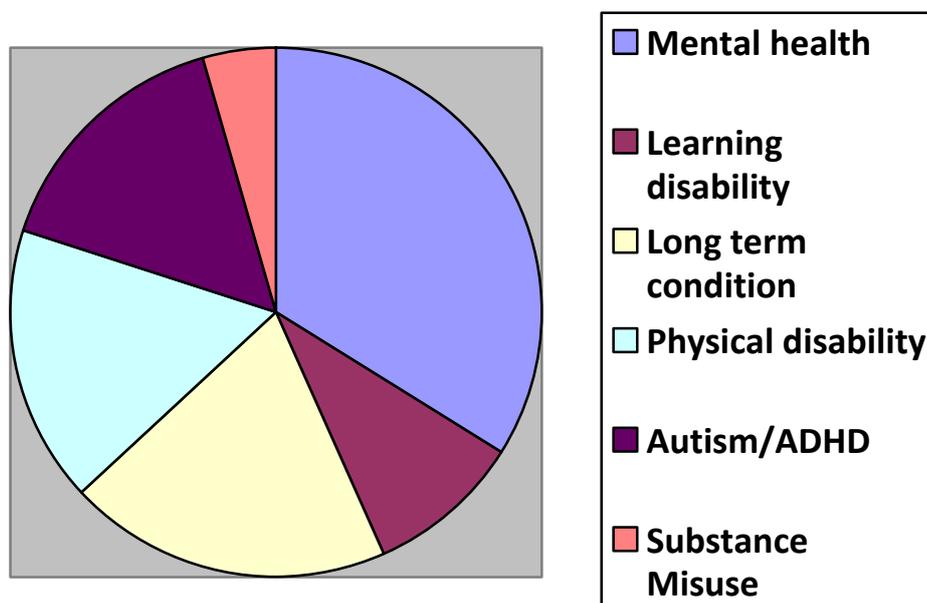
The 2011 Census identified *[number to be added when available]* Young Carers in Calderdale under the age of 25. Calderdale Young Carers Service is in contact with 271 young carers under the age of 25 of which 226 are aged between eight and 15 and 44 are aged 16 and over. 9% of the young carers are from Black Minority and Ethnic communities.

This is nearly double the 138 young carers they were in contact with in 2009 when the last carers strategy was published. So again the staff are stretched to capacity and have reluctantly had to establish a waiting list which currently (June 2012) has 23 young carers on it who wait an average of three months to access the service. Young carers who are finding things difficult are seen more quickly.

**Chart 5 – Relationship to young carer**



**Chart 6 – Condition of person cared for by young carer**



### **PARENT CARERS OF DISABLED CHILDREN**

According to the Joint Strategic Needs Assessment there are between 1,360 and 2,447 children in Calderdale experiencing some form of disability. Families who have a disabled child often find it difficult to access services such as leisure unless they have an extra pair of hands to support children's needs. Families can easily become isolated by both the practical and emotional issues of caring for a disabled child and this social isolation can affect self-esteem for both parents and children.

In Calderdale less than 30% of families with a child with complex needs have access to a social worker, with many families not receiving any form of short break. Many families say that 'I don't need any support' or 'I can manage on my own', yet this is often not the case and families find themselves isolated by both the physical and emotional demands of caring for a severely disabled child.

Families of disabled children are often isolated in respect of locality based services as they access many services centrally.

Many families' lives are often very complicated, they have to plough their way through a maze of services, appointments and assessments. This is on top of supporting a child with very complex needs.

In 2009 a study on the emotional wellbeing of parents of disabled children was commissioned by the PCT. Many of the parents involved reported, 'being at the end of their tether', or were prescribed anti-depressants. Research from Contact a Family and Joseph Rowntree Foundation highlights the fact that families with disabled children face high levels of day to day need and have high levels of unmet need in health and/or social care. These issues are raised locally on both the Disabled Children's Strategy Board and the Adult Mental Health Strategy Group.

- The average income of families with a disabled child is nearly 25% less than a family without a disabled child.
- It costs up to three times as much to raise a disabled child, yet only 16% of mothers of disabled children work compared to 61% of the population as a whole.
- Only a minority of families receive formal social care support, yet all families are likely to face some additional pressure, stress and cost when caring for a disabled child or young person.
- Disabled children are 13 times more likely to be excluded from school.
- There are well over 750 disabled children with complex needs living in Calderdale and around a total of 2000 children with educational statements
- Traditional childcare for disabled children is significantly more difficult to come by and typically costs significantly more.

## OUR PRIORITIES IN CALDERDALE

Our priorities for carers over the next three years are as follows. The actions relating to these priorities are listed in the action plan.

- a) Raise awareness of carers and young carers
- b) Identify hidden carers
- c) Provide up-to-date information
- d) Health and well-being of carers
- e) Carers breaks
- f) Offer carers personal budgets
- g) Link with GPs/Health Professionals to support carers
- h) Young carers and young adult carers
- i) Support for carers who work or want to work
- j) Support for carers from diverse communities
- k) Support for growing numbers of dementia carers
- l) Support for carers of people with substance misuse issues
- m) Support for carers of people with mental health issues especially those in hospital or A&E
- n) Carers who suffer financially due to benefit changes
- o) Support for ex-carers

### **a) Raise awareness of carers and young carers**

Many people who are caring for someone do not think of themselves as carers, they just see themselves as carrying out their duty as a family member, partner or friend, especially if the person they care for has become ill gradually e.g. with a deteriorating condition such as Parkinsons or Dementia, or if they are caring for an older person who has become more frail over a period of time. It is often a crisis that makes them more likely to rethink their role, for example, a sudden deterioration in the condition of the person they care for or reaching a point where they can no longer cope alone and need outside support. People who become carers suddenly such as relatives of someone who has had a stroke or accident resulting in

disability, may feel thrown into the role of carer, especially if that will mean changes to their lifestyle to fit in caring for their relative.

In order to help people identify themselves as carers and for other people to identify carers, it is important to raise awareness about what a carer is. One issue with people identifying themselves as carers is that the term “carer” is also used for staff who are carers, e.g. home care assistants, support workers, personal assistants. One local council are proposing to stop using the word carer to refer to paid carers, and remove the term from job titles, job descriptions and council publications, so that where the term carer is used it always means family carer.

Young carers are even more unlikely to identify themselves as such, so it is even more important to raise awareness amongst people who come into contact with young people, such as school staff and health professionals.

**We will:**

- **Promote the free online training at [www.learningpool.com/yohrelearning](http://www.learningpool.com/yohrelearning) to raise awareness of carers and young carers**
- **Encourage GP practices to use ‘Supporting Carers – An action guide for GPs and their teams’**
- **Raise awareness of carers and young carers through notice boards eg in GP surgeries and information stands e.g. during Carers Week**
- **The Young Carers Service raises awareness of the needs of young carers through information sessions for staff**

**b) Identify Hidden Carers**

Some groups of carers are harder to reach, these include:

- Carers from Black Asian Minority and Ethnic (BAME) groups, including Eastern European groups
- Carers whose first language is not English
- Carers who have difficulty reading and writing

- Carers with disabilities including sensory impairments or learning disabilities
- Carers who are from or who care for someone from Lesbian Gay Bisexual or Transgender (LGBT) communities

For many of these groups, leaflets and posters will not be accessible to them. They may need information translated into a different language or in Braille or on CD. They may also be unaware of or reluctant to engage with carers support services or support groups. A more effective way of engaging with these groups is to go to them, but there could be language barriers. Calderdale NHS employ Community Engagement Officers who are bilingual and have made effective links with the local Asian communities and set up new community groups such as “GupShup” which is a Neighbourhood Group for Asian Women aged over 50. Also Together for Mental Wellbeing employ a bilingual Carer Support Worker to support carers of people with mental health problems - this is effective and the worker is involved with the Asian Women’s Carers Support Group that Calderdale Carers Project run.

The Brunswick Centre works with people from the LGBT community and provides support for people with HIV and their carers. Calderdale Carers Project have an information stand at the annual Calderdale Pride event and have information for carers from the LGBT community, as do some national organisations such as the Alzheimer’s Society.

Sometimes people with learning disabilities who live with their older parents gradually become mutual carers. As their parents get older and more frail, they can take on more of the household tasks, such as cleaning, shopping or gardening. They may even have to help their mum or dad with tasks such as dressing or getting around safely. As their parents still care for them, they are “mutual carers”. The Community Learning Disability Team are aware of such situations, and an Older Carers Database is kept so that older carers of people with a learning disability can be kept an eye on.

Sainsbury's have a scheme for identifying hidden carers which they piloted in their Torbay store and are now rolling out across the country. It involves providing some carer awareness for their checkout and pharmacy staff and then providing leaflets for customers who are carers and directing them to an information stand in store which is staffed by local carers centre staff. Calderdale Carers Project and other carers workers are keen to be involved with this scheme when it comes to Halifax.

**We will:**

- **Work with other organisations to identify carers, e.g. Sainsbury's, pharmacists and GP practices.**
- **Provide information for carers to the LGBT community, eg. through The Brunswick Centre, Calderdale Pride and the Calderdale LGBT Network.**
- **Provide information in other languages or formats or use translators or bilingual workers where needed.**

**c) Provide up-to-date information**

A key message from "Recognised, valued and supported: next steps for the Carers Strategy" (2010) is: *"carers need better and timely access to information – on the illness or condition of the person they are caring for; on appropriate caring; on accessing benefits and other support; and on financial and employment issues"*

Calderdale Carers Project provide information packs to new carers, as well as specific information where requested. Other voluntary organisations, such as Calderdale Alzheimer's Society and Together for Mental Wellbeing, provide detailed information about the condition of the person cared for. Information needs to be up-to-date and it also needs to be timely, particularly if you are caring for someone with a progressive condition such as Alzheimer's or Motor Neurone Disease. To be faced with details of the long term effects of such conditions at diagnosis could be overwhelming.

A wide range of information for carers is available on the internet, both local and national, and an increasing number of carers have access to the

internet, but there will always be some carers without the ability, finances or desire to access information online. Therefore information needs to be available in different formats. The Calderdale Council website has a Social Care and Well-being Hub which has details of organisations and events for vulnerable people and carers.

**We will:**

- **Promote access to local and national resources and websites for carers.**
- **Calderdale Carers Project will continue to provide regular Carers Newsletters and Carers Information Packs.**
- **Ensure up to date information is included on the websites of local statutory bodies**

**d) Health and Wellbeing of Carers**

One of the four priority areas for the refreshed national carers strategy is supporting carers to remain mentally and physically well. *“There is a clear relationship between poor health and caring that increases with the duration and intensity of the caring role. Those providing high levels of care are twice as likely to have poor health compared with those without caring responsibilities.”*

Carers Scotland carried out a survey “Sick, tired and caring: The impact of unpaid caring on health and long term conditions” (2011) which found that 96% of carers who responded reported that caring had impacted negatively on their health and wellbeing:

- 70% reported back or shoulder pain
- 86% reported stress, anxiety and depression
- 41% suffered a range of illnesses which were caused or exacerbated by their caring role, including arthritis, high blood pressure, diabetes, chronic fatigue/fibromyalgia, IBS.
- 34% experienced exhaustion
- 10% experienced frustration, resentment and anger
- 54% felt isolated

The National Carers Strategy Demonstrator Sites included health and wellbeing checks for carers at six sites across the UK. What was covered in the health checks varied but included physical health, mental health, stress and emotions, lifestyle and safety. 95% of carers who had a health check felt it was a good way to support carers and around 25% reported health improvements as a result including looking after their health, diet, ability to cope, taking regular exercise and dealing with stress.

Although health checks for carers are not routinely offered in Calderdale, several GP practices offer them on request, and many GP practices offer flu jabs to carers. Emotional support is offered through a range of carer support groups and services as well as a free counselling service through Calderdale Carers Project.

Carers often neglect their own health because they are focussed on supporting their loved one. It may be that they have no time or energy left to deal with their own health issues, or that there is no one else to support their loved one whilst they attend a hospital appointment. Occasionally, carers will even put off operations because of this. The Targeted Support Fund has been able to pay for support for a cared for person so that the carer could attend hospital for a cataract operation.

**We will:**

- **Identify carers as a key group for flu immunisation and other relevant vaccines.**
- **Encourage carers to complete back-up plans.**
- **Encourage carers to register as carers with their GP and encourage GP practices to register carers.**
- **Encourage carers not to neglect their own health and offer support for their cared for person so that they can attend health appointments, where possible.**
- **Work closely with GP practices and other health services to offer carers more flexible services, for example longer appointments.**

- **Continue to offer emotional support to carers through a range of support groups and support services and a free counselling service.**
- **Continue to fund and deliver Looking After Me courses for carers.**
- **Develop a plan for health checks for carers.**

#### **e) Carers Breaks**

Having a break from caring, whether it's a couple of afternoons a week or a week's respite regularly, enables carers to carry on caring. Having some regular time off to recharge your batteries is something that many carers value highly. Carers breaks can be during the daytime, eg. when the person they care for is attending a day service or overnight if they have regular respite. Both these breaks involve the cared for person having a break out of the house.

Sitting services are also available to stay with the cared for person in their own home, and this is often preferable for people with dementia who can get confused in different surroundings. The Support in Mind scheme, run by Calderdale Council, provides specialist support for people with dementia and their carers - it involves supporting people in their own home or taking them out.

Calderdale Council's Shared Lives scheme provides daytime support and overnight respite for people in the homes of shared lives carers. This is for older people and people with a learning disability or mental health need. This provides an alternative break for carers and people who would rather spend time in a normal family home.

The National Carers Strategy Demonstrator Sites focused on carers breaks in many areas. Before the projects, 80% of carers had not been able to take a break for more than a few hours and the benefits included improvements in relationships, ability to cope, looking after own health and dealing with stress.

Sometimes carers want to have a break with the person they care for, such as a holiday or a few days respite together. This gives them a change of scene and a break from their regular routine of shopping, cooking and cleaning. This is also something that can be provided, where appropriate.

Personal Budgets are available for people to pay for their own holiday or support, rather than traditional respite breaks. They can also fund daytime support as an alternative to attending a council run day centre. This gives people more choice and flexibility, and allows them to be a part of the community.

**We will:**

- **Continue to offer a wide range of breaks for carers.**
- **Continue to offer Personal Budgets as a way of funding individual breaks.**

**f) Carers Personal Budgets**

We currently offer a Carers Small Grant Scheme which is up to £250 for carers to spend on themselves, eg. on a holiday or gym membership or a dishwasher. We plan to change this to Carers Personal Budgets in 2013. This will be a similar one off payment for carers to use to pay for anything that will enhance their life. As there is a limited budget for this, carers will complete a carers assessment form to assess their level of need, and Carers Personal Budgets will be awarded by a panel to those in most need.

**We will:**

- **Offer Personal Budgets to carers from April 2013.**
- **Monitor the scheme to ensure that carers in most need are the ones that benefit from it.**

### **g) Link with GPs and Health Professionals to support carers**

Calderdale Carers Project works to maintain good links with GP Practices. Several surgeries provide Carers Noticeboards for the Carers Project to display information. Information stands have been provided in GP surgeries and Calderdale Royal Hospital during Carers Week.

GPs register carers who are patients at their practice, and an annual survey is carried out to establish figures. 963 carers were registered at GP practices in Calderdale in 2012.

Carers come into contact with other health professionals such as district nurses, occupational therapists and hospital staff. Gateway to Care which is the access point for Adult Health and Social Care services, now contains health staff as well as social care staff to provide a joined up service.

Another group of health professionals who come into contact with carers is pharmacists, and this is a group that may be helpful in identifying hidden carers. This is an area we would like to explore.

#### **We will:**

- **Identify other groups of health professionals who can identify carers, such as pharmacists.**
- **Consider identifying carers champions in each GP practice.**
- **Maintain good links with GP practices to identify and support carers.**

### **h) Young Carers and Young Adult Carers**

As the refresh of the national carers strategy states: *“Inappropriate caring roles or long hours of caring are likely to have a detrimental impact on young carers’ lives, including their health and educational achievement. Young carers should be supported to achieve their potential and to have the same opportunities that other young people enjoy.”*

Young carers often care for a parent with a physical or mental health condition, some help their parents to care for their brother or sister who has

a physical or learning disability. Some young carers support their parent who has a substance misuse issue and Lifeline run a support group for these young people which is well attended.

Having the responsibility of caring for a relative at a young age can be difficult for some young people. Young carers have to grow up quickly and can miss out on having fun with their friends.

Calderdale Young Carers Service are in contact with 270 young carers aged between 8 and 18. They provide information and advice, regular newsletters, weekly group sessions, social events, advocacy and individual support. It is estimated that there are around 30 young carers in a typical secondary school. They have a schools liaison worker and they have recently launched a school passport which young carers can show to their teacher if they need time out to make a phone call or help with their homework.

The service has been running for over 8 years and some of the young carers have turned 18 but have continued to be supported by the service. The Young Adult Carers Group is for young people aged between 18 and 25 and they are currently being supported to make the transition to Calderdale Carers Project.

**We will:**

- **Support young adult carers to make the transition to Calderdale Carers Project.**
- **Promote school passport in primary schools.**
- **Seek funding for additional staff hours to reduce waiting list of young carers.**

**i) Support for carers who work or want to work**

“Recognised, valued and supported: next steps for the Carers Strategy” (2010) states the importance of supporting carers to stay in work if they want to and puts an emphasis on employers being flexible and understanding in order to achieve this.

*“It is crucial that we place a much higher priority on supporting people of working age with caring responsibilities to remain in work, if they wish to do so....many carers currently feel forced to give up work because they feel they have no other options available to them.”*

There are over 3 million working carers in the UK, about half of them work full-time. 80% of carers are of working age and of the carers who don't work over 40% say they would like to.

For people who become carers to remain in work, employers need to be flexible but for many carers replacement care is needed. If the person they care for needs someone to call in and get their lunch whilst the carer is working that's fairly straightforward but if they can't be left at all and need full-time replacement care that is more difficult to arrange. Personal budgets can be used but paying for full-time care to replace what a carer does for free is very costly - this shows how much money carers save the local authority.

As local authorities are currently faced with a large reduction in government funding, funding replacement care so that carers can work is becoming more difficult. However, local authorities have a duty of care to disabled adults so if there is no relative available to provide care during the daytime then alternative support has to be funded.

Assistive technology can provide carers with peace of mind whilst they are at work. Community care alarms or devices such as falls detectors or medication dispensers can alert help if people fall and remind people to take their tablets. This is being used to encourage people to remain independent and to support carers.

People who have to give up work to become full-time carers for a relative can face financial hardship. Carers Allowance is the lowest paid earnings replacement benefit at just £58.45 per week (2012/13). Carers can earn up to £100 a week on top of this, so part-time work may be a better option, if

possible. Carers on low incomes may also be entitled to income support, housing benefit and council tax benefit.

For many carers, work provides social contact and financial reward and can be a welcome break from their caring role. For others, the pressure of juggling a job and being a carer can be too stressful and they feel they have to give up their job. As “Recognised, valued and supported: next steps for the Carers Strategy” (2010) states: *“The Government wants to empower carers to fulfil their work potential, to protect their own and their family’s current and future financial position and to enjoy the health benefits and self-esteem that paid employment or self-employment can bring. Yet many carers currently feel forced to give up work because they feel they have no other options available to them.”*

Following the national carers strategy in 2008, Jobcentre Plus were given funding to help those carers who want to go back to work. This scheme is called Work Focused Support for Carers and provides advice on training, finding a job and local replacement care. It can pay for replacement care whilst carers attend interviews or training courses. Nationally, 6,620 carers have taken part in this scheme with 300 attending a training course (Feb 2011).

**We will:**

- **Provide information to employers and managers on supporting carers in the workplace.**
- **Provide information and advice to carers who feel they have to give up work to become full-time carers.**
- **Ensure that information, advice and support is available to working carers by promoting the Carers Direct Helpline and carers websites, and offering support and events for carers outside normal working hours.**
- **Continue to promote the Jobcentre Plus scheme to support carers who want to go back to work.**
- **Provide alternative support for carers who want to remain in work, where possible.**

## **j) Support for carers from diverse communities**

The Carers UK report “Half a Million Voices: Improving outcomes for BAME carers” (2011) identified the following challenges which are faced by Black, Asian and Minority Ethnic carers:

- Stigma of caring for certain conditions, e.g. HIV or mental illness
- Language/literacy barriers combined with lack of knowledge of entitlements
- Cultural barriers which hinder access to services
- A lack of culturally appropriate practical services
- Fact that BAME communities are seen as homogenous and yet are extremely diverse
- Particular barriers faced by refugees
- Misconceptions about extended family support that may not exist
- Faith is not always explored in relation to BAME issues
- A stronger BAME carer voice is needed

There is established support for Asian carers in Calderdale such as the Asian Women’s Carers Support Group and Together for Mental Wellbeing’s Asian carers support worker. One community which is growing is the Eastern European one. There is no specific carer support for this group although as religious and cultural differences are less of an issue than they are with the Muslim community, the main area of support they may need is translation, if there are difficulties with spoken or written English.

### **We will:**

- **Maintain specialist support for the Asian community.**
- **Offer information in other languages and use translators where necessary.**
- **Investigate the need for support for carers from other communities, eg Eastern European.**

### **k) Support for the growing number of dementia carers**

As the number of older people is forecast to rise dramatically over the next few decades, the number of people with dementia is also set to increase rapidly. Dementia UK estimates that 1 in 20 people over 65 and 1 in 5 over 80 are affected by dementia. In Calderdale national prevalence rates indicate that there are around 2,303 people with dementia which is set to rise by 75% to 4,042 people by 2030.

The Alzheimer's Society report "Support. Stay. Save. Care and support of people with dementia in their own homes" (2011) reported that carers of people with dementia experience greater strain and distress than carers of other older people and that 52% of carers for people with dementia are not getting sufficient support to enable them to carry out their caring role.

Caring for someone with dementia can be very physically and psychologically demanding, particularly as the illness progresses. Many dementia carers are close family members – wives, husbands, daughters and sons who have to deal with increasing needs for care and support alongside the mental and physical decline of their loved one often to a point where they are no longer recognised.

Ongoing education about dementia and coping strategies as the condition progresses is key and the Alzheimer's Society can provide this either locally or nationally. This can be provided by telephone support, home visits and a comprehensive range of information through leaflets or the website.

During 2011 Calderdale Council and Calderdale NHS tendered for support services for people with dementia and their carers. Calderdale Alzheimer's Society was successful and received £150,000 per year until March 2013 for services which include dementia cafés, dementia carer support groups and dementia advisers. The Council's Adults Health and Social Care Scrutiny Committee which is made up of local councillors has been involved in reviewing dementia services in Calderdale. A report entitled "A Bold Approach" has been produced which makes a number of recommendations

including that Calderdale should become a dementia-friendly borough by April 2014.

**We will:**

- **Continue to provide support to people with dementia and their carers through dementia cafés and support groups.**
- **Refer people with dementia and their carers to the Alzheimer’s Society for specialist support and information about coping strategies, not just at diagnosis but as the condition progresses.**
- **Recognise the increased stress and demands that carers of people with dementia are often under.**

**l) Support for carers of people with substance misuse issues**

Carers of people with drug or alcohol issues are possibly the least likely group to identify themselves as carers. They often have to deal with stigma or illegality issues and may be involved in hiding the effects of addictive behaviour from friends, relatives and neighbours. Adfam’s 2009 report “We Count Too” said that drug misuse can have a devastating impact on families and identified four key areas:

- Fear and loss of control
- Anger and betrayal
- Guilt and responsibility
- Shame and isolation

An estimated 2.5 million people are affected by a relative’s drug use, and Al-Anon estimate that over 13 million people are affected by a family member’s alcohol misuse. As substance misuse is a specialist area, people with knowledge of the effects of substance misuse are often best placed to provide support to family members and carers. This may come from substance misuse services or from other relatives or users who have been through it. Generic carers services are also available for support but may not have the same level of understanding of what caring for someone with a substance misuse issue is really like. We need to ensure that substance

misuse carers are included and don't miss out on things like carers assessments, carers personal budgets, information and support.

**We will:**

- **Meet regularly with substance misuse carers workers to update each other and discuss carers issues.**
- **Monitor the support for carers of people with substance misuse issues and respond to needs for additional support as these occur.**

**m) Support for carers of people with mental health issues especially those in hospital or A&E**

A specialist carer support service for carers of people with mental health issues in Calderdale is commissioned from Together for Mental Wellbeing. The service is well used by carers in the community and the staff have recently started offering support to carers of people on the acute ward of The Dales. Carers of people with enduring mental health issues can also face stigma and lack of understanding from others, leading to isolation. Relatives of people who enter The Dales in mental health crisis, especially if it's the first time, can be confused and in need of information and support. As the patients are the priority for the staff at the Dales, carers can get overlooked, so to have carers support workers available at regular times on the ward is very useful.

Another issue for people with mental health needs and their carers is that if they have a mental health crisis, out of hours, they are directed to A&E which is a stressful environment with little understanding of mental health issues. They then have to wait to be seen by a mental health professional within 4 hours. A long wait in A&E out of hours is a stressful experience for someone in mental health crisis and their carer, and is likely to increase both their anxiety levels. This issue has been discussed at the SWYPFT Dialogue Groups and a Task and Finish Group is being established to discuss it further. Solutions could be a private room for people to wait in and a reduction in the 4 hour target.

**We will:**

- **Continue to offer support to carers of people with mental health issues at The Dales.**
- **Monitor the outcomes of the Task and Finish Group on people attending A&E in mental health crisis.**

**n) Carers who suffer financially due to benefit changes**

The current changes in the benefits system are having a significant effect on a number of carers and people who are cared for. This is creating more work for carers workers who are having to prioritise carers who are in financial crisis, which means they have no time to spend identifying new carers. Some carers support services are already stretched to the point that they have stopped advertising their service or seeking new referrals as they are struggling to support the number of carers they are working with.

Changes from Incapacity Benefit to Employment Support Allowance and changes to Housing Benefit have led to a loss of income for a number of carers and cared for people. They have also caused a great deal of stress and anxiety to those involved, particularly people with mental health issues. Further changes from Disability Living Allowance to Personal Independence Payments and withdrawal of funding for legal aid advice for welfare benefits matters (as well as debt, employment and many housing matters) will mean more people lose income and are caused stress and anxiety. From April 2013 they will no longer be able to get support to appeal from the Citizen's Advice Bureau.

**We will:**

- **Consult and involve partner agencies to consider how carers affected can be supported and the limits to such support.**
- **Look into the possibility of a joint bid to fund a benefits worker in the voluntary sector to support carers and cared for people with benefits advice and appeals.**

- **Continue to offer the caseworker service through the Carers Project and seek further funding for the second caseworker post when this runs out in August 2013.**
- **Ensure that carers' needs are taken into account in new council benefit schemes e.g. council tax support.**

#### **o) Support for ex-carers**

Ex-carers are often overlooked. If they become an ex-carer when the person they are caring for dies they will be dealing with the bereavement, or if the person they are caring for has to go into a home because they can no longer meet their needs, they may be dealing with feelings of loss and guilt. They may have lost touch with friends and family, or have had to give up work whilst they have been caring. So they could be very isolated and they will have lost their identity as a carer.

They may also struggle financially if they have been relying on benefits as Carers Allowance stops 8 weeks after the cared for person has died, and Attendance Allowance and Disability Living Allowance usually stop four weeks after the cared for person moves into a home. If the carer is of working age, they may then be expected to sign on to Jobseeker's Allowance and look for work.

Calderdale Carers Project recognise the need for support for ex-carers and have set up a support group for them called the "Carefree Group." They have also used ex-carers as volunteers and are currently researching the needs of this group and hope to find funding to support them further.

#### **We will:**

- **Research the needs of ex-carers and look for funding to support ex-carers.**
- **Continue to offer support to ex-carers through the Carefree Group.**

## ACHIEVEMENTS IN CALDERDALE

There have been a number of achievements for carers in the last three years, within the Council, Calderdale Carers Project, SWYPFT, Calderdale PCT and the voluntary sector.

Calderdale Council appointed a part-time Carers Development Worker in December 2009. As part of this role the following new initiatives have been set up:

- Carers Champions – carers champions from each social work team meet quarterly for an update on national and local developments for carers and to have the opportunity to feedback any issues from their team regarding carers.
- Staff Carers Forum – this is a monthly drop-in session to provide information, advice and support to members of staff who are carers for a friend or relative. Free head, neck and shoulder massages were provided to working carers during Carers Week.
- A “Supporting Carers at Work” guide has been produced with advice for working carers and their managers. This has been distributed to local employers.
- An annual GP survey has been set up to identify how many carers are registered with GP practices in Calderdale:  
2010 - 620 carers  
2011 – 864 carers  
2012 – 982 carers
- Carers Small Grants of up to £250 have continued to be offered to carers who are on a means tested benefit or receive Carers Allowance. Around 160 carers a year benefit from this scheme. Carers can spend the money on anything that will benefit them as a carer, e.g. a weekend away, therapy sessions, gym membership or household goods such as a tumble dryer. The grants are much appreciated by carers and can make a real difference:

*“It gave me time for myself and enabled me to relax and unwind. This grant was a really good pick-me-up and made me feel rewarded for the hard work I put in than can often go unnoticed.”*

- The Carers Assessment process has been redeveloped. Following some regional research and consultation with carers, a new form has been produced which can be completed by carers themselves or with support from workers from Adult Social Care or the voluntary sector e.g. Calderdale Carers Project, Together and Calderdale Alzheimer’s Society. The completed carers assessments are now stored electronically and the outcomes are recorded. In 2011/12 – 177 carers assessments were completed, double the figure for the year before.
- Calderdale was fortunate to be part of the National Development Team for inclusion (NDTi) Better Lives Project during 2011. This project was carried out in three different parts of the country (Calderdale, Suffolk and Wolverhampton) and it was for older carers of adults with learning disabilities. Families were supported through a person-centred planning process to look at future support needs for their son or daughter. Two people moved out of the family home into supported living accommodation as a result of the project, and one lady started attending a day service having previously been at home all week. Other participants have plans in place for the future which they are now starting to put into action.

Calderdale Carers Project have continued to provide a wide range of support to carers including information and advice, regular newsletters, carers support groups, activities and a free counselling service. They have also provided the following:

- Looking After Me courses – these were started in 2007 as part of the Partnership for Older People’s Project (POPPs) and proved very popular with carers. To date 170 carers have completed the Looking After Me course. One carer commented:

*“The groups are intimate and friendly and a safe place to share our struggles with one another. It has helped me to know as a carer I am not alone. We've learned to relax, how to create some ‘me time’ without feeling guilty. How to look at different ways to solve our problems.”*

- Targeted Support Fund – this was set up in 2009 with some funding from the Community Foundation for Calderdale. It is a fund to help carers in crisis and can pay for practical assistance such as moving a bed downstairs so that someone can return from hospital, or a short term sitting service to provide relief for the carer, for example while the carer is in hospital. The initial funding was for six months and the results were so good that the Council has continued to fund it. A small amount of money can make a big difference to a carer in crisis.

*Calderdale Carers Project has been able to use their Targeted Support Funding to make a real difference to the lives of carers and the cared for. A while ago we home visited a carer who was caring for his wife who had Alzheimer's. The couple received no help from social services as they felt they could manage by themselves. However the carer had had to give up attending a social club once a week which he really enjoyed, due to his caring responsibilities. The Carers Project explained that it may be possible for the carer to receive help with his wife from a support worker on a weekly basis to allow him to attend the club. A referral was made to social services but the Carers Project were able to use the targeted support funding to set up a support worker for the following week. Now the carer is able to have a few hours to himself a week, but also due to the brilliant work of the support worker the cared for gets involved in cooking a fresh meal every week, which also takes further pressure away from the carer who has his tea ready when he gets home!*

*Calderdale Carers Project has also been able to use its targeted support funding to help carers who are struggling financially. We have recently been supporting a carer who has been in real financial difficulties due to awaiting an appeal regarding her benefits. The carer, who cares for her mother, had been struggling to afford the bus fare to travel to her mother's, so on some occasions she had been walking a fair distance to ensure her mother was*

*cared for. We have been able to use targeted support funding to purchase monthly bus tickets for the carer easing the financial pressures on her and ensuring that she is able to continue to care for her mother.*

- The Carers Case Worker service which was also set up as part of POPPs has continued to provide a valuable service, providing advice and support to carers on an individual basis. As there was a large demand for this service, additional funding was sought from Lloyds TSB for an additional part-time case worker for two years who started in August 2011.
- The Young Carers Service has continued to provide support to young carers with fortnightly activity sessions, individual support, advocacy, newsletters, special projects, residentials and more.
- Young Adult Carers – the Young Carers Service and Calderdale Carers Project obtained some Carers Innovation Funding in 2010 to work with Young Adult Carers to produce a DVD and put on training sessions with staff. The Council are now funding a Carers Project worker to support the Young Adult Carers to make the transition from the Young Carers Service to Calderdale Carers Project.

South West Yorkshire Partnership NHS Foundation Trust (SWYPFT) support carers in the following ways:

- A Carers Dialogue Group is held bi-monthly where carers can meet with service managers to discuss any issues which arise. Carers workers also attend the meetings, which are a useful way of exchanging information and keeping up to date.
- A Carers Information Pack of comprehensive information about mental health conditions and support available is being updated.
- A Carers Charter is being developed across the trust.

Calderdale PCT/Clinical Commissioning Group (CCG) supports carers by:

- Providing some funding to Calderdale Carers Project, including funding for the Looking After Me courses for carers.
- Providing funding for a number of respite services for older people, people with disabilities and people with drug and alcohol problems
- Providing funding for a number of day services providing care and activities in a safe environment for older people, people with disabilities and people with drug/alcohol problems
- Passing on section 256 funding to Calderdale Council to carry out activities with health benefits, covering the following services:
  - Funding for Calderdale Alzheimer's Society to provide support to carers of people with dementia.
  - Funding for the Stroke Association to provide information, advice and support to carers of people who have had a stroke.
  - Funding for Telecare services which provide peace of mind for carers, especially those who don't live with the person they care for.
  - Funding for Reablement services which work with people to help regain their independence so they are less dependent on services and carers.

The following new services have been set up in the voluntary sector to support carers:

- Together for Mental Wellbeing provide a carer support service to carers of people with mental health issues. They have three part time workers based with the Community Mental Health Teams, including one bilingual female Asian worker. They offer information, advice and support to carers and can visit them at home and have recently started providing advice to relatives visiting the acute ward at The Dales.

*Mr M was referred to Together for Mental Wellbeing as a long term carer to his wife. As English is not his first language, the carer support worker was also able to support him by speaking with him in his own language, communicating on his behalf and translating for him. She was able to support him emotionally and practically through a referral for an occupational therapy assessment for some equipment to reduce the day to day strain of his caring role.*

- Loved Ones Unite – this group was set up by a mother who lost her son to drug abuse. It offers support to friends and relatives of people with drug and alcohol issues. One-to-one emotional support is provided and a monthly support group is held at Conn3ct.
- Stroke Association – they offer an Advice, Information and Peer Support Service and can visit people who have had a stroke and their families.
- Calderdale Alzheimer’s Society – increased funding has led to a number of dementia cafés and carers support groups across Calderdale. The dementia cafés offer a chance for people with dementia and their carers to socialise with others, and there is a carers support groups for carers who support their relative at home, and one for carers whose relative is in a residential or nursing home.
- Overgate Hospice has set up a carers support group for carers of people who use the hospice. It meets fortnightly to provide emotional support and advice to carers.
- Al-Anon – a new group has been set up in Halifax for families and friends of alcoholics. They meet weekly for support.

## **Appendix 1 – Financial contributions by statutory organisations**

The financial contributions made by Calderdale Council and Calderdale PCT/CCG to support carers in 2012/13 are set out below.

Financial contributions for future years will be determined through the respective organisations' budget-setting processes.

### Calderdale Council

The overall budget for Adults Health and Social Care in is £53 million. This covers support to people with physical disabilities, learning disabilities, mental health needs and older people. The majority of the support Adults Health and Social Care provide contribute to carers breaks and support for carers. These include:

- Direct Payments
- Homecare
- Outreach
- Day services
- Home based respite
- Residential respite
- Information and advice services

These services are accessed through community care assessments and service users are required to make a financial contribution for care services if they are able, which is determined through a financial assessment.

### Calderdale PCT/CCG

Calderdale PCT/CCG provides a total of £985,000 including £668,000 which funds services which contribute to providing carers with a break:

- £463,000 on day services
- £205,000 on respite services

The PCT/CCG also funds a number of more general services that benefit carers, for example information and advice services for older people.

The PCT/CCG has also passed on £2.5m in section 256 funding (money enabling local authorities to carry out activities with health benefits) to Calderdale Council to fund telecare, reablement, Alzheimer's and Stroke services – these can also be of benefit to carers.

## CALDERDALE CARERS STRATEGY 2012-2015

## ACTION PLAN

The table below sets out actions planned by organisations to deliver the strategy. The delivery of these actions is dependent upon ongoing consultation and securing agreement for funding through local business planning processes. Progress on actions will be monitored through the quarterly Carers Strategy Group meetings, and reported on an annual basis to the organisations involved in delivering the strategy through each organisation's governance processes.

ACTION	RESPONSIBLE ORGANISATION	COMPLETION DATE
<b>Raise Awareness of Carers and Young Carers</b>		
Promote the free online training at <a href="http://www.learningpool.com/yohrelearning/">www.learningpool.com/yohrelearning/</a>	Carers Development Worker, Calderdale Council (CMBC)	March 2013
Encourage GP practices to use 'Supporting carers – An action guide for GPs and their teams.'	Calderdale PCT/CCG	March 2013
Notice boards in GP Surgeries and information stands e.g., during National Carers Week in June.	Calderdale Carers Project Together for Mental Wellbeing	March 2014

Young Carers raise awareness to professionals through presentations.	Calderdale Young Carers Service	December 2015
<b>Identify Hidden Carers</b>		
Work with other organisations to identify carers, e.g. Sainsbury's, pharmacists and GP practices.	Calderdale Carers Project Carers Development Worker, CMBC, Calderdale PCT/CCG Together for Mental Wellbeing	March 2013
Provide information for carers to the LGBT community e.g. through The Brunswick Centre, Calderdale Pride and the Calderdale LGBT Network.	Calderdale Carers Project Carers Development Worker, CMBC Calderdale PCT/CCG Together for Mental Wellbeing	March 2014
Provide information in other languages or formats and use translators or bilingual workers where needed.	Calderdale Council Calderdale PCT/CCG Together for Mental Wellbeing	December 2015
<b>Provide Up-to-date Information</b>		
Provide information for carers on Calderdale PCT/CCG website.	Calderdale /PCT CCG	December 2012
Work with GP practices to use carers register to ensure people are keyed into the right support.	Calderdale PCT/CCG	June 2013
Promote access to local and national resources and websites for carers, e.g. Carers Direct.	Calderdale Carers Project Calderdale PCT/CCG Together for Mental Wellbeing Calderdale Alzheimer's Society	March 2014

Provide regular carers newsletters and carers information packs.	Calderdale Carers Project	March 2014
<b>Health and Well-being of Carers</b>		
Identify carers as a key group for flu immunisation and other relevant vaccines.	Calderdale PCT/CCG	December 2012
Encourage carers to complete back-up plans	Adults Health and Social Care, CMBC Calderdale Carers Project Calderdale PCT/CCG Together for Mental Wellbeing	March 2013
Encourage carers to register with their GP and encourage GP practices to register carers.	Calderdale Carers Project Carers Development Worker, CMBC Calderdale PCT/CCG Together for Mental Wellbeing	March 2014
Encourage carers not to neglect their own health and offer support for the person they care for so that they can attend health appointments, where possible.	Adults Health and Social Care, CMBC Calderdale Carers Project Together for Mental Wellbeing	March 2014
Work with GP practices and other local health services to offer carers more flexible services.	Calderdale PCT/CCG	March 2014

Continue to offer emotional support to carers through a range of support groups and support services and a free counselling service.	Calderdale Carers Project Together for Mental Wellbeing Calderdale Alzheimer's Society	March 2014
Continue to fund and deliver Looking After Me courses for carers.	Calderdale PCT/CCG Calderdale Carers Project	March 2014
Develop a plan for carer health checks.	Calderdale PCT/CCG	March 2014
<b>Carers Breaks</b>		
Continue to offer a wide range of breaks for carers.	Adults Health and Social Care, CMBC Calderdale PCT/CCG	December 2015
Continue to offer Personal Budgets as a way of funding individual breaks.	Adults Health and Social Care, CMBC	December 2015
<b>Carers Personal Budgets</b>		
We will offer personal budgets to carers.	Adults Health and Social Care, CMBC Calderdale Carers Project	From April 2013 onwards
Monitor the scheme to ensure that the carers in most need are the ones that benefit from it.	Adults Health and Social Care, CMBC Calderdale Carers Project Together for Mental Wellbeing Calderdale Parents & Carers Council	From April 2013 onwards

<b>Link with GPs and Health Professionals to support carers.</b>		
Identify other groups of health professionals who can identify carers, such as pharmacists.	Carers Development Worker, CMBC Calderdale Carers Project Calderdale PCT/CCG	March 2013
Consider identifying carers champions in each GP practice.	Calderdale PCT/CCG	June 2013
Maintain good links with GP practices to identify and support carers.	Calderdale Carers Project Carers Development Worker, CMBC Together for Mental Wellbeing	March 2014
<b>Young Carers and Young Adult Carers</b>		
Support young adult carers to make the transition to Calderdale Carers Project and/or Together for Mental Wellbeing	Calderdale Young Carers Service Calderdale Carers Project	March 2013
Promote school passport in primary schools.	Calderdale Young Carers Service	March 2014
Seek funding for additional staff hours to reduce waiting list of young carers.	Calderdale Young Carers Service Carers Development Worker, CMBC	March 2014
<b>Support for carers who work or want to work</b>		
Provide information to employers and managers on supporting carers in the workplace.	Carers Development Worker, CMBC	March 2013

Provide information and advice to carers who feel they have to give up work to become full-time carers.	Calderdale Carers Project Carers Development Worker, CMBC	March 2014
Ensure that information, advice and support is available to working carers by promoting the Carers Direct Helpline and carers websites, and offering support and events for carers outside of normal working hours.	Calderdale Carers Project Carers Development Worker, CMBC Together for Mental Wellbeing Calderdale Alzheimer's Society Calderdale PCT/CCG	March 2014
Continue to promote the Jobcentre Plus scheme to support carers who want to go back to work.	Calderdale Carers Project Carers Development Worker, CMBC Together for Mental Wellbeing	March 2014
Provide alternative support for carers who want to work, where possible.	Adults Health and Social Care, CMBC	December 2015
<b>Support for carers from diverse communities</b>		
Continue to offer specific bilingual support for Asian carers.	Calderdale Carers Project Together for Mental Wellbeing Calderdale Alzheimer's Society	March 2014
Investigate the need for support for carers from other communities, e.g. Eastern European.	Carers Development Worker, CMBC Calderdale Carers Project Together for Mental Wellbeing	March 2014

<b>Support for growing number of dementia carers</b>		
Continue to provide support to people with dementia and their carers through dementia cafes and support groups.	Calderdale Alzheimer's Society Calderdale Council Calderdale PCT/CCG	March 2014
Refer people with dementia and carers to the Alzheimer's Society for specialist support and information about coping strategies, not just at diagnosis but as the condition progresses.	Adults Health and Social Care, CMBC Calderdale Carers Project Calderdale PCT/CCG	March 2014
Recognise the increased stress and demands that carers of people with dementia are often under.	Calderdale Alzheimer's Society Adults Health and Social Care, CMBC Calderdale PCT/CCG	December 2015
<b>Support for carers of people with substance misuse issues</b>		
Meet regularly with substance misuse workers to update each other and discuss carers' issues.	Carers Development Worker, CMBC	December 2015
Monitor the support for carers of people with substance misuse issues and respond to needs for additional support as these occur.	Carers Development Worker, CMBC	December 2015

<b>Support for carers of people with mental health issues especially those in hospital or A&amp;E</b>		
Monitor the outcomes of the Task and Finish Group on people attending A&E in mental health crisis.	Calderdale Carers Dialogue Group	March 2013
Continue to offer support to carers of people with mental health issues at The Dales. Review this periodically.	Together for Mental Wellbeing	March 2014
<b>Carers who suffer financially due to benefits changes</b>		
Consult and involve partner agencies to consider how carers affected can be supported and the limits to such support.	Calderdale Carers Project Together for Mental Wellbeing	March 2013
Ensure that carers' needs are taken into account in new council benefit schemes e.g. council tax support	Adults Health and Social Care, CMBC	
Look into the possibility of a joint bid to fund a benefits worker in the voluntary sector to support carers and cared for people with benefits advice and appeals.	Calderdale Carers Project	March 2013

Continue to offer the Caseworker service through the Carers Project and seek further funding to for the second caseworker post when this runs out in August 2013.	Calderdale Carers Project	August 2013
<b>Support for ex-carers</b>		
Research the needs of ex-carers and look for funding to support them.	Calderdale Carers Project	March 2013
Continue to provide support for ex-carers through the Carefree Group.	Calderdale Carers Project	March 2014
<b>Other areas</b>		
Identify a carers champion on the CCG Governing Body.	Calderdale PCT/CCG	December 2012
Develop carer standards to be included in all new service specifications.	Calderdale PCT/CCG CMBC	March 2013
Undertake engagement/involvement work with carers to inform the commissioning of services.	Calderdale PCT/CCG CMBC	Ongoing