



# **A Health Needs Assessment for Carers: Young People and Adults in Devon**

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# **Health Needs Assessment of Carers: Young People and Adults in Devon**

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## 1. Executive Summary

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- 1.1 This report describes the specific health needs affecting carers, the impact of the changing demography of Devon, the health in-equalities that exist and makes recommendations for action.
- 1.2 This report has been written following consultation with the public and professionals on the Devon Joint Strategic Needs Assessment (Joint Strategic Needs Assessment, published February 2008) and was highlighted by the Devon Director of Public Health in the Annual Public Health report 2007-08.
- 1.3 Nationally<sup>1</sup> nearly 21% of carers providing more than 50 hours of care report that they are not in good health, compared with only 11% of the non-carer population. Nationally, the impact on the mental health in women who care is significantly greater than that of non carers. One of Devon's strategic ambitions<sup>2</sup> is to increase by 10% the number of people with moderate to severe dementia who are helped to remain at home by 2013. A range of support to carers including respite (day and overnight) and emergency care will be essential if this ambition is to be realised.
- 1.4 There is significant evidence to support the fact that carers of all ages are a vulnerable group at a disproportionate risk of experiencing health in-equalities. At present one in five carers give up work to care and the link between poverty and poor health is well established.
- 1.5 Projections for the population change across Devon between 2006 and 2031 suggest that the overall population will increase from 741,000 to 967,900. The 0-14 and 15-64 age groups are forecast to increase by around 20% with larger increases, of 75% and 85%, being anticipated in the over 65 and 75 population. By 2031 forecasts suggest that there will be 270,500 people over the age of 65 and 146,600 over the age of 75. The demographic changes in Devon will increase the number of and the demands on carers and their needs need to be taken into account and met if they are to enjoy a life of their own. Care planning and an offer of a carer's assessment is a crucial part of the process and have been included as a key local outcome in World Class Commissioning.
- 1.6 More than 72,400 people (of all ages) in the Devon Primary Care Trust area are carers (Census 2001 figures). 12% of who were aged 65 years and over, with 6,300 or 9% aged 75 years of age or over. 14,400 (20%) provide more than 50 hours of care and support per week. From the Census 2001 figures it would indicate that in Devon there are just over 2,000 young carers (less than 3% of carers of all ages), although it is believed that there are significantly more. Roughly half of the young carers (1,084) are aged below 16 years of age.
- 1.7 There are county wide and local mechanisms for engaging with carers and seeking their views on priorities for action. The five core strategic initiatives already agreed are listed in Figure 1 below.

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<sup>1</sup> 2001 Census © Crown Copyright - Click Use license number C2008002351

<sup>2</sup> Devon County Council and Devon Primary Care Trust, ...'the Way Ahead – Five years of improvement, Health and Social Care in Devon 2008-2013'

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**Figure 1: Five Core Strategic Initiatives for Engaging with Carers<sup>2</sup> (and Appendix 7) – not in any priority order**

1. Improving understanding
2. Improving identification, access and plans
3. Meeting carers needs
4. Improving support at times of crisis
5. Recognising and working with carers as partners in care

- 1.8 Targets have already been set and agreed to improve the percentage of carers who are offered an assessment and care plan be it advice or advice and specific support such as planned short breaks. Targets should be set for those receiving palliative care.
- 1.9 Information regarding carers is held by a number of different agencies including primary care, social care, the voluntary sector and external agencies such as the Department of Work and Pensions (DWP) albeit this does not include information on people not of working age. Consideration needs to be given as to the value locally of a shared central register, subject to carers consent, to improve the understanding of local needs and the ability to target resources most effectively. The option to commission a local survey of the health of carers to enhance local intelligence should be considered.
- 1.10 The role of the new joint strategic commissioning manager post in optimising the sharing of good practice and ensuring a consistent approach, i.e. health checks, where necessary, should support an effective way forward.

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## **2. Recommendations**

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### **Existing Initiatives**

- 2.1 Five core strategic initiatives, listed below, already underpin the ambitions outlined in the joint five year plan<sup>2</sup> and measurable achievements are detailed in Appendix 2 (not in any priority order):
- improving understanding
  - improving identification, access and plans
  - meeting carers' needs
  - improving support at times of crisis
  - recognising and working with carers as partners in care

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2.2 Work-streams to support these initiatives are in place (see Appendix 7) and additional recommendations as a result of this health needs assessment include care plans, intelligence and health screening / checks.

2.3 Carer support should be particularly targeted at those who:

- are caring for more than 50 hours per week
- are over the age of 65
- are caring for someone with a deteriorating physical condition or with mental health problems
- are making the transition from caring for a child in transition to adulthood

## Care Plans

2.4 Currently Devon assesses about 9% of the total identified population of 72,400 carers and targets to improve performance year on year have been set (Appendix 2).

2.5 There is a need to ensure that the care plans for those receiving palliative care using the Gold Standard Framework (GSF) and Liverpool Care Pathway (LCP) build in the needs of carers into the planning process and there is a mechanism to monitor and report on compliance.

## Intelligence

2.6 Currently registers are held by Primary Care, Social Care and the voluntary sector. There is an opportunity, at local level, to develop a better mechanism to share data on carers currently held by schools, the health services, Devon County Council and the voluntary sector. Subject to a carer's consent, a central register could be developed locally to help support a shared understanding of needs and target resources to meet the needs. The Department of Work and Pensions can provide information on the proportion of people claiming carers allowance but this only includes those of working age.

2.7 The health needs identified in this report have been extracted from national surveys and the 2001 Census. Current information does not bring to light the actual service needs for individuals beyond very basic factual health and social care needs. Consideration should be given to the option of commissioning an external agency to undertake a local survey on the health of carers, using a nationally recognised generalised research tool. This would further improve Devon's understanding of the health needs of local carers (young and adult).

## Health Checks / Screening

2.8 A consistent approach to undertake the annual health checks should be agreed locally if they are rolled out following national and local pilots. Anonymised data from these health checks should be made available to improve local understanding of the health needs of carers and how they can best be met.

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## 3. Introduction

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- 3.1 The requirement to undertake a health needs assessment of carers of all ages was highlighted in my Annual Public Health report 2007-08 published in 2008. Devon County Council (DCC) and the Devon Primary Care Trust (DPCT) recognise that carers of all ages want 'a caring system on their side and a life of their own'.
- 3.2 The definition of a 'carer' is problematic, as many people do not see themselves as a carer or undertaking anything other than that which is expected of them, given the circumstances they find themselves in. Caring takes place within a context of culture, love, duty and obligation and carers as such are not therefore a homogenous group<sup>3</sup>.
- 3.3 Core elements of a carer as defined in this health needs assessment includes the fact that extra, unpaid responsibilities are undertaken in order for the person cared for to remain in the community. Paid support workers or personal assistants are not considered to be carers in the context of this report.
- 3.4 More than 72,400 people (of all ages) in the Devon Primary Care Trust (DPCT) area act as a carer (Census 2001 figures). 12% of who were aged 65 years and over, with 6,300 or 9% aged 75 years of age or over. 14,400 (20%) provide more than 50 hours of care and support per week. The Census 2001 figures indicate that in Devon there are just over 2,000 young carers aged 0 - 19 years (less than 3% of carers of all ages), although it is believed that there are significantly more. Roughly half of young carers, 1,084, are aged below 16 years of age. Across the county the numbers varied with the highest proportion in several of the North Devon towns and the coastal areas of East Devon, those areas with a higher older-age population.
- 3.5 Devon reflects the national picture in that women are more likely to be carers than men. Nationally<sup>4</sup>, 54% of carers were women, when looking after someone in the same household and this rose to 60% when looking after someone living elsewhere. The dependant person was more likely to be female than male and if living alone, is more likely to be aged 65 or older. The more hours of care per week given, the more likely there is a negative impact on the health and wellbeing of the carer leading to in-equalities in health.
- 3.6 The health needs identified in this report have been extracted from national surveys and the 2001 Census. Consideration should be given to the option of commissioning an external agency to undertake a local survey on the health of carers, using a nationally recognised generalised research tool. This would further improve Devon's understanding of the health needs of local carers (young and adult).
- 3.7 However, in the absence of reliable local data I would commend the findings in this report to inform future joint strategic commissioning decisions. The new joint strategic commissioning manager has the responsibility to work in partnership with carers and others to ensure resources are allocated to

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<sup>3</sup> Social services inspectorate (1995) What next for carers? Findings from a social services inspectorate project. London: Department of Health.

<sup>4</sup> National Statistics: Carers 2000 J. Maher, H. Green, London The Stationary Office 2002

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optimise the health and wellbeing of present and future carers, so that they can fulfil their caring role and at the same time have a life of their own.

- 3.8 Commissioning arrangements are currently devolved between children's services and those for adults. There is a need to ensure there are sound mechanisms in place to share good practice, develop effective performance monitoring tools and handle transitional needs effectively.
- 3.9 A co-ordinated and consistent Devon-wide approach needs to be developed to identify 'hidden carers', including those from minority groups. Where there is a lack of evidence to support the funding of new or innovative projects, that carers would value, a robust evaluation process needs to be put in place. Results should be fed back to commissioners and carers in order to inform future commissioning decisions and investments. Regular reporting of progress against locally agreed targets should also be routinely available.
- 3.10 A number of targets, actions and ambitions to be achieved have already been agreed locally<sup>2</sup> and they are set out in Appendix 2. In addition to those areas of work consideration should be given to:
- monitoring care plans for people receiving palliative care as well as in the areas already agreed
  - establishing a shared central register of carers
  - achieving consensus across Devon on the "health check" tool to be used for identifying the health needs of carers - this will ensure there is an ongoing mechanism across Devon to assess health needs of carers and influence commissioning decisions.

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## 4. Background

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### Purpose of a Health Needs Assessment (HNA)

- 4.1 The National Institute for Health and Clinical Excellence (NICE) describes a health needs assessment as a '*systematic method for reviewing the health needs of a particular population leading to agreed priorities and resource allocation which will lead to improved health and reduced health in-equalities*'.<sup>1</sup>
- 4.2 This report will focus on the health needs of young, adult and older carers.

### Defining a Carer

- 4.3 When attempting to provide a definition of a carer one of the key challenges is that many people do not see themselves as a carer or undertaking anything other than that which is expected of them given the circumstances they find themselves in. Caring takes place within a context of culture, love, duty and obligation<sup>1</sup> and carers as such are not therefore a homogenous group<sup>3</sup>.

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- 4.4 For the purposes of this report, the definition used in a joint publication between the Princess Royal Trust for Carers and the Royal College of General Practitioners<sup>5</sup> has been used:
- 4.5 “A carer is someone who, without payment, provides support to a partner, child, relative, friend or neighbour who could not manage without their help. This could be due to age, physical or mental illness, addiction. A young carer is one under the age of 18 and carries out significant caring tasks and assumes a level of responsibility for another person which is inappropriate to their age”.
- 4.6 Concern has been expressed locally in Devon that this definition excludes people with learning disabilities (life long intellectual impairment) who may not necessarily have a physical or mental disability but who still require care. The definition<sup>5</sup> complements those used in the General Household Survey of 2000<sup>6</sup> and the Government report on Carers June 2008<sup>7</sup>. For the purpose of this report the health needs of carers of people with a learning disability are included.
- 4.7 The key factors to note when defining a caring role is that it is unpaid, involves extra responsibilities due to the physical, sensory or intellectual disability, and/or mental ill health and or age of the person who is cared for, in order for them to remain in the community. Paid support workers or personal assistants are not included in the definition of carers.

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## 5. Context

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### National Policies

- 5.1 The white paper ‘Our Health, Our care, Our Say’<sup>8</sup>: announced a new deal for carers encompassing four key parts: a comprehensive national information service, a training programme for carers ‘Caring with confidence’, improved emergency care cover and a ten year framework to meet carer’ needs.
- 5.2 Another report<sup>9</sup> highlighted the need to recognise the expertise carers have when undertaking the single assessment process, person centred plans, developing personalised budgets and direct payments.
- 5.3 The ten year framework<sup>7</sup>, published this June sets out the steps to be taken in partnership that builds on the first carers strategy, Caring for Carers, published in 1999.

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<sup>5</sup> Supporting Carers: An Action Guide for General Practitioners and Their Teams’, The Princess Royal Trust for Carers and the Royal College of General Practitioners October 2007

<sup>6</sup> National Statistics: Carers 2000 J. Maher, H. Green, London the Stationary Office 2002

<sup>7</sup> Carers at the Heart of 21<sup>st</sup> Century Families and Communities – a caring system on your side, a life of your own’ (HM Government - June 2008).

<sup>8</sup> Our Health, Our Care, Our Say - a new direction for community services (Department of Health, January 2006

<sup>9</sup> Putting People First: A shared vision and commitment to the transformation of adult social care ( Local Government Association, ADASS, Department of health, December 2007)

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- 5.4 The strategic vision within the ten year framework<sup>7</sup>, is that by 2018..." carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring whilst enabling the person they support to be a full and equal citizen.."
- 5.5 The vision is underpinned by a number of principles. Carers will be:
- respected as expert care partners and will have access to integrated and personalised services to support them
  - able to have a life of their own alongside their caring role
  - supported and not forced into financial hardship by their caring role
  - supported to stay physically and mentally well and treated with dignity
  - children and young people will be protected from in-appropriate caring and have the support to achieve the outcomes in Every Child Matters<sup>10</sup> i.e. being healthy, staying safe, enjoy and achieve, make a positive contribution and achieve economic well-being
- 5.6 The areas for national development over the next three years are summarised in Appendix 1 and additional investment nationally has been identified.

## Legislative Framework

- 5.7 As well as the additional financial support to local authorities, four changes or additions to existing legislation have been introduced.
- 5.8 First, four principal changes contained in the Carers and Disabled Children Act 2000 are:
- councils were given more powers to support carers by providing services to carers directly
  - carers were given the right to an assessment independent of the person they care for
  - local authorities were enabled to make direct payments to carers
  - councils were given options to support flexibility in provision of short breaks through the short-break voucher scheme.
- 5.9 The second, three main changes to the existing law around carers' include:
- a duty on councils to inform carers, in certain circumstances, of their right to an assessment of their needs

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<sup>10</sup> Every Child Matters: Change for Children, November 2004 HM Government

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- when assessing a carer's needs, councils must now take into account whether the carer works or wishes to work, undertakes or wishes to undertake education, training or leisure activities
- there should be co-operation between authorities in relation to the provision of services that are relevant to carers - to note that a draft protocol related to cross boundary issues across England has been produced.

5.10 In the third area, the Work and Families Act 2006 extended the right to request flexible working to employees who care for adults. This does not mean, however, that the request will be honoured. This built on the introduction (through the Employment Act 2002) of the right to request flexible working for parents of children under the age of six (or 18 if the child is disabled). An independent review<sup>11</sup> has now recommended that the right to request flexible working should be extended to cover parents of children aged 16 and under. The Government's response to this review is awaited.

5.11 Finally, legislation on equalities and the Disability Discrimination Act(s) recognises the right of people in society to equal citizenship, which will benefit both carers and the people that they care for and support.

## Regional Ambitions

5.12 The draft NHS South West three-year strategic frame work<sup>12</sup> did not include a specific section on carers. Carers' needs, however, were implicitly recognised in several of the chapters including those related to long term conditions, mental health and end of life care. A brief summary of the ambitions relevant to carers is detailed in the Figure 2 below:

**Figure 2: The Draft Framework for Improving Health in the Southwest 2008/09 -2010/11<sup>12</sup>**

Topic	Ambition
<b>Long-term conditions</b>	To fully implement the quality requirements of the National Service Framework for Long-term Conditions ahead of the national timescale of 2015
	To fully implement the standards set out in the National Service Frameworks for Older People, Coronary Heart Disease, Diabetes and Renal Services ahead of the national timescales for their delivery
	To ensure that all people with a long-term condition have an action plan that supports their self-management by 31 <sup>st</sup> March 2010
	Each locality to have a co-ordinated multi-disciplinary team approach for long-term conditions by 31 <sup>st</sup> march 2010 with a single point of access
	Increase year-on-year by 5% per annum the percentage of carers of people with a long-term condition who have a carer assessment and support
<b>Mental</b>	Full implementation of the standards set out in the National Service

<sup>11</sup> Imelda Walsh's independent review (Right to request flexible working: A review of how to extend the right to request flexible working to parents of older children, Department for Business, Enterprise and Regulatory Reform, 2008

<sup>12</sup> Draft Strategic Framework for Improving Health In the South West 2008/09 to 2010/11 NHS South West, May 2008

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<b>Health</b>	Framework for Mental Health ahead of the national timescale of 2010
	Improved access for new service users: assessments completed within eight weeks by 31 March 2009 and within four weeks by 31 March 2011. This includes responding to the particular needs of mothers, children, adolescents, adults of working age and older people
	Improved access and support for carers: assessments and care plans for the identified main carer completed within four weeks of a newly referred service user assessment by 31 March 2010
	All people with depression and anxiety to have access to psychological therapies in every Primary Care Trust by 31 March 2011, three years ahead of the national requirement
	All people diagnosed with dementia to have a care plan within four weeks of their diagnosis by 31 March 2010
	All people receiving NHS care for physical conditions to have access to a full range of psychiatry services by 31 March 2009
	All people with an enduring mental health problem who are no longer under the care of a community mental health team have a named care co-ordinator linked to their general practice surgery by 31 March 2010
	All Primary Care Trusts should develop at least three best practice pathways, based on published guidelines from the National Institute for Health and Clinical Excellence and incorporate service user-led outcomes in their commissioning requirements by 31 March 2011
<b>End of Life Care</b>	All health communities will be able by 31 March 2011 to identify the number of people with a plan for their death and to report the percentage of cases where the preference about place of death has been delivered
	People can access at all times the 'basic building blocks' for effective care (community nursing, equipment, drugs and the patient plan) by 31 March 2011
	Providing support at home will lead to reduced unplanned admissions to hospital from nursing homes in the last 12 months of life by 10% per annum (from the 2007-08 baseline) for each of the next three years

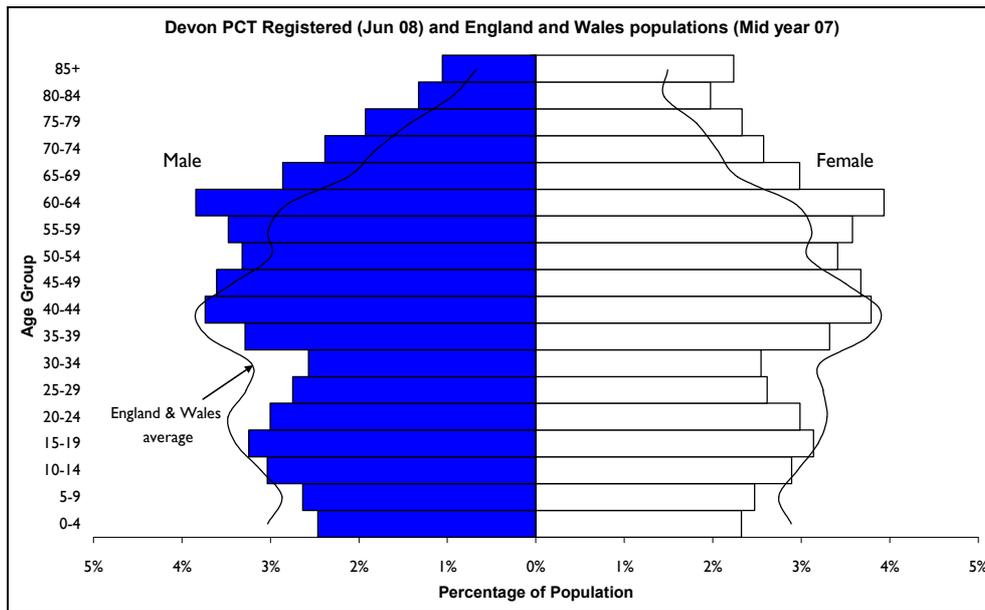
### Local Strategies

- 5.13 Five core strategic initiatives for carers underpin the health and social care ambitions in Devon<sup>2</sup>, not in any priority order, and Appendix 7:
- improving understanding
  - improving identification, access and plans
  - meeting carers needs
  - improving support at times of crisis
  - recognising and working with carers as partners in care.
- 5.14 In support of these initiatives a number of measurable achievements have been described in the five year Devon plan<sup>2</sup>, see Appendix 2 and Appendix 7.

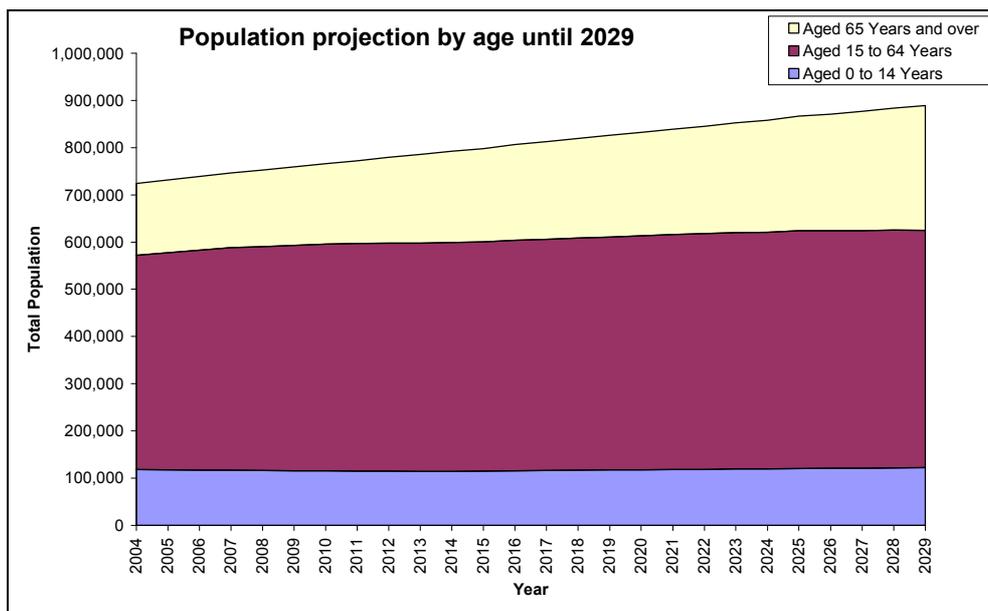
## 6. Demography and Population Projections

6.1 The GP registered population of Devon Primary Care Trust totalled 755,601 as of 30 June 2008 of which 386,043 were female and 369,558 were male. A graphical representation (population pyramid) further breaking the population down by sex and age band is shown in Figure 3 along with a second graph, Figure 4, showing population projections up until 2029.

**Figure 3: Devon Primary Care Trust Registered (Jun 08) and England and Wales Populations (Mid year 07)**



**Figure 4: Population Projection by Age until 2029**



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- 6.2 Projections for the population change across Devon between 2006 and 2031 suggest that the overall population will increase from 741,000 to 967,900. The 0-14 and 15-64 age groups are forecast to increase by around 20% with larger increases, of 75% and 85%, being anticipated in the over 65 and 75 population. By 2031 forecasts suggest that there will 270,500 people over the age of 65 and 146,600 over the age of 75.
- 6.3 In Devon as in England and Wales, females live longer than males and life expectancies for both males and females have increased over time. The average (2004-06) life expectancy for both men and women in Devon is better than the England and Wales average, see Figure 5 below:

**Figure 5: The Average (2004/06) Life Expectancy for Both Men and Women in Devon and the England and Wales Average**

2004-2006		
	Males	Females
Devon Primary Care Trust	78.8	83.0
England and Wales	77.2	81.5

- 6.4 The demographic profile for Devon indicates that more people are living longer and the prevalence of long term illness and chronic disease will increase. These changes and the policy to care for people at or close to home will also lead to greater pressures on carers in the future.

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## 7. Prevalence and Epidemiology and Impact on Health

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- 7.1 More than 72,400 people (all ages) in the Devon Primary Care Trust area are carers (Census 2001 figures). 12% of who were aged 65 years and over, with 6,300 or 9% aged 75 years of age or over. 14,400 (20%) provide more than 50 hours of care and support per week.
- 7.2 From the Census 2001 figures, it would indicate that in Devon there are just over 2,000 young carers (less than 3% of carers of all ages), although it is believed that there are significantly more. Roughly half of these young carers, i.e. 1,084, are aged below 16 years of age.
- 7.3 In Devon, as reflected nationally, women are more likely to be carers than men. The characteristics of carers, i.e. 'who is caring for whom?' described in the 2000 General Household Survey (GHS) report<sup>6</sup> (self defined measures of care giving), indicated that 54% of carers were women, when looking after someone in the same household, which rose to 60% when looking for someone living elsewhere. The dependant person was more likely to be female than male and if living alone, is more likely to be aged 65 or older. The more hours of care given a week, the more likely it is to be provided by a women rather than a man.

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**Figure 6: The Health of the Person Cared for<sup>5</sup>**

- 62% (i.e. the majority of carers) were looking after someone with a physical disability
- 6% for someone with a mental disability including dementia
- 18% were looking after someone with both a mental and physical disability - which could include learning disability, dependency on drugs and or alcohol
- 14% stated the person they cared for was because the person was old

7.4 Issues for people who have a learning disability cannot be separated out from those with a physical or mental disability, as the General Household Survey<sup>6</sup> did not structure the questionnaire so that this could be done. Whilst not all people with an intellectual impairment have a physical and mental disability it is generally recognised that they have greater health needs than the general population, which will inevitably impact on the health of their carers.

**Figure 7: The Type of Help Carers were Giving<sup>5</sup>**

- 71% of carers provide practical support (preparing a meal, shopping or doing laundry)
- 60% kept an eye on someone
- 55% provided company
- 35% provided physical help (e.g. with walking)
- 26% ,just over a quarter, provided more intimate forms of personal care (washing)
- 22% assisted by administering medicines

7.5 The sample size of the 2000 General Household Survey<sup>6</sup> was 13,000 nationally, with 10% from the South West. Given the sample size, it is not appropriate to present results at Devon County level; however we have used national estimates and applied these to our 2001 Census carers information<sup>3</sup>.

7.6 The 2001 Census<sup>1</sup> included for the first time, a question copied below, on the provision of unpaid care.

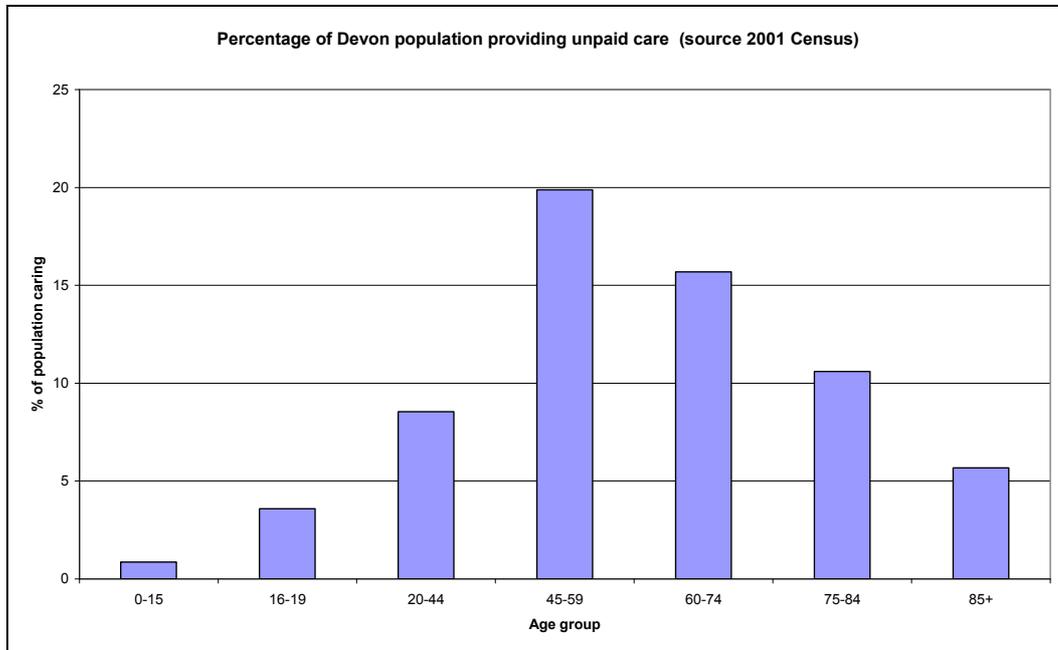
*'Do you look after or give any help or support to family members, friends or neighbours or others because of: long term physical or mental ill health or disability or problems related to old age?'*

7.7 The graphs/charts below contain 2001 Census data for the Devon population.

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7.8 The graph below (Figure 8) shows the percentage of Devon population providing unpaid care by age group. The majority are 45 years of age and older.

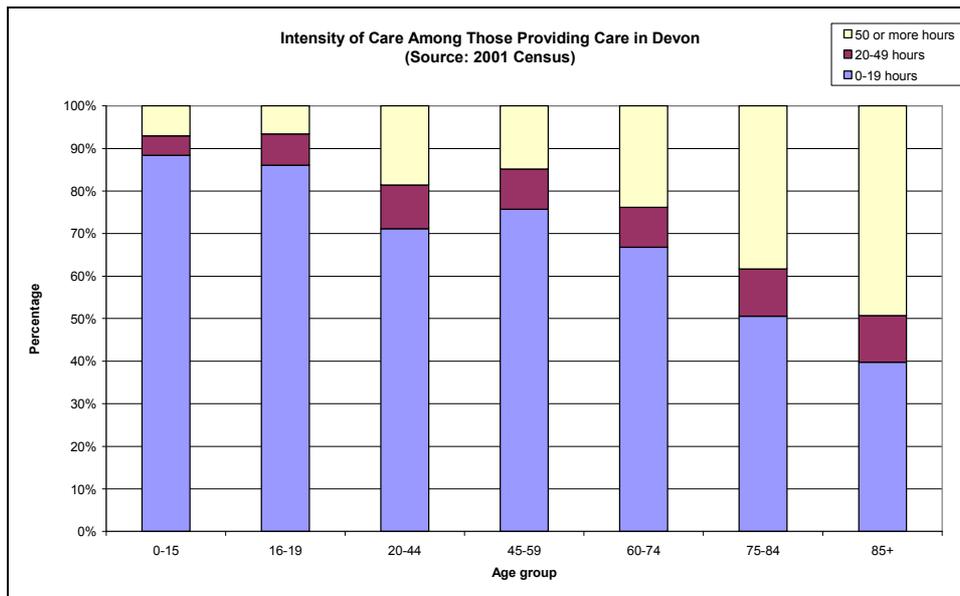
**Figure 8: Percentage of Devon Population Providing Unpaid Care (Source 2001 Census)**



7.9 The graph below (Figure 9) shows the increased intensity of care given, measured in hours per week by age group across Devon as a whole. People aged 75 and over offer more hours per week in a caring role. Those aged 20-44 offer similar hours of support as those aged 60-74 who are in the retirement age-bracket, although the 60 plus age-group still offer more support in the 50 plus hours per week category.

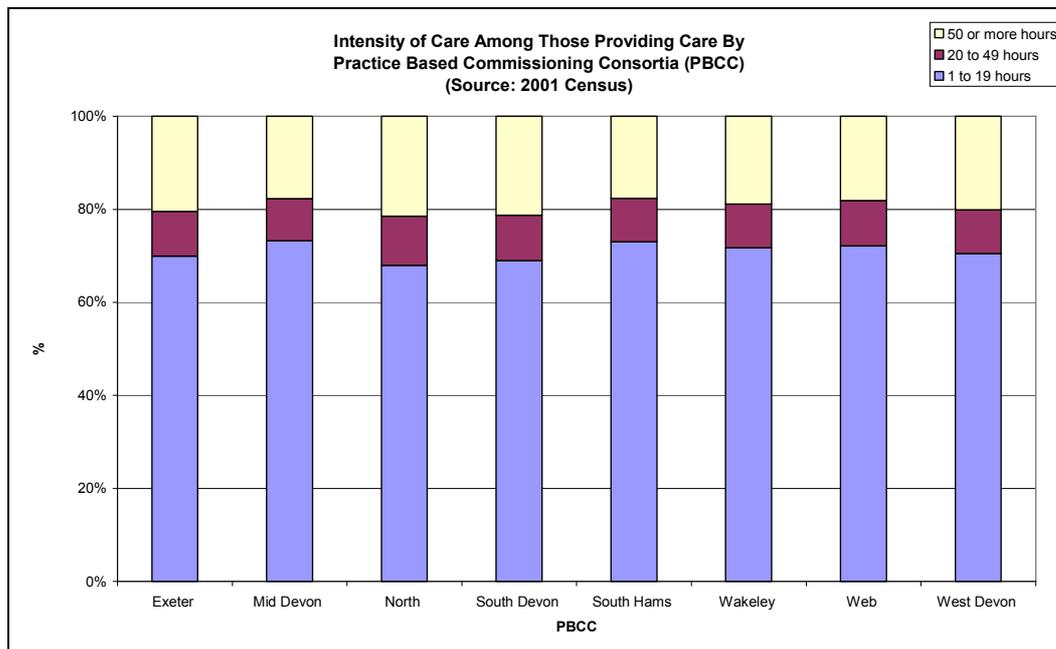
**Figure 9: Intensity of Care among those Providing Care in Devon (Source 2001 Census)<sup>1</sup>**

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7.10 The graph below (Figure 10) shows the increased intensity of care given, measured in hours per week by Practice Based Commissioning Consortia (PBCC). The consortia with higher age profiles show slightly higher levels of care provided over 50 hours per week.

**Figure 10: Intensity of Care among those Providing Care by Practice Based Commissioning Consortia (Source 2001 Census)<sup>1</sup>**

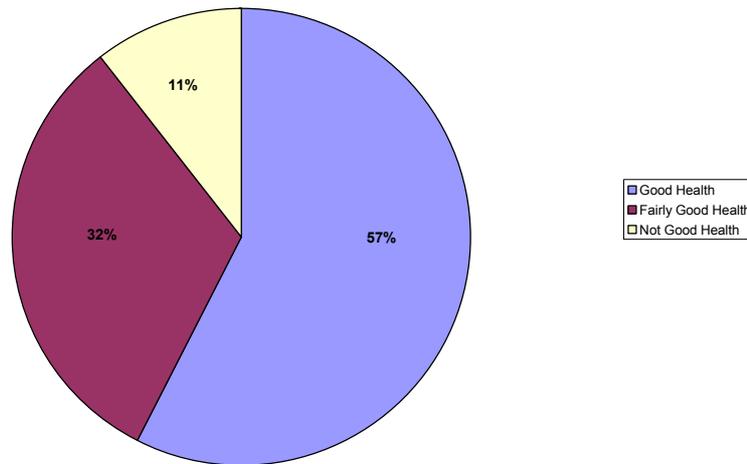


7.11 The pie chart below (Figure 11) describes the self reported health of carers (of all ages) in Devon. 57% say they are in good health whereas evidence would suggest that there is an under reporting of poor health as carers view the health of the person they care for as more important.

**Figure 11: Self Reported Health of Carers in Devon (Source 2001 Census)<sup>1</sup>**

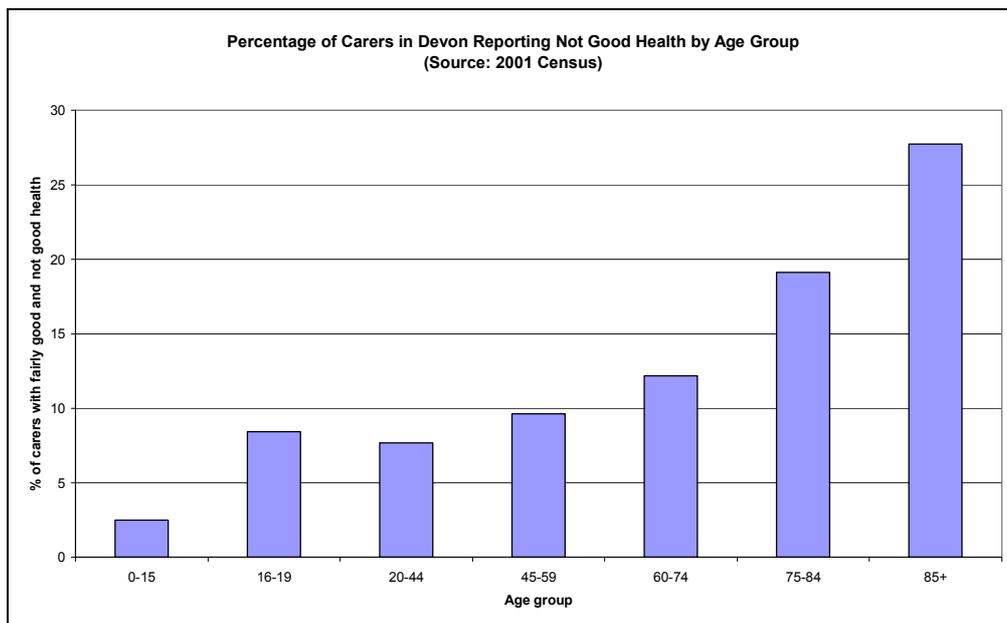
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Self Reported Health of Carers in Devon (source 2001 Census)



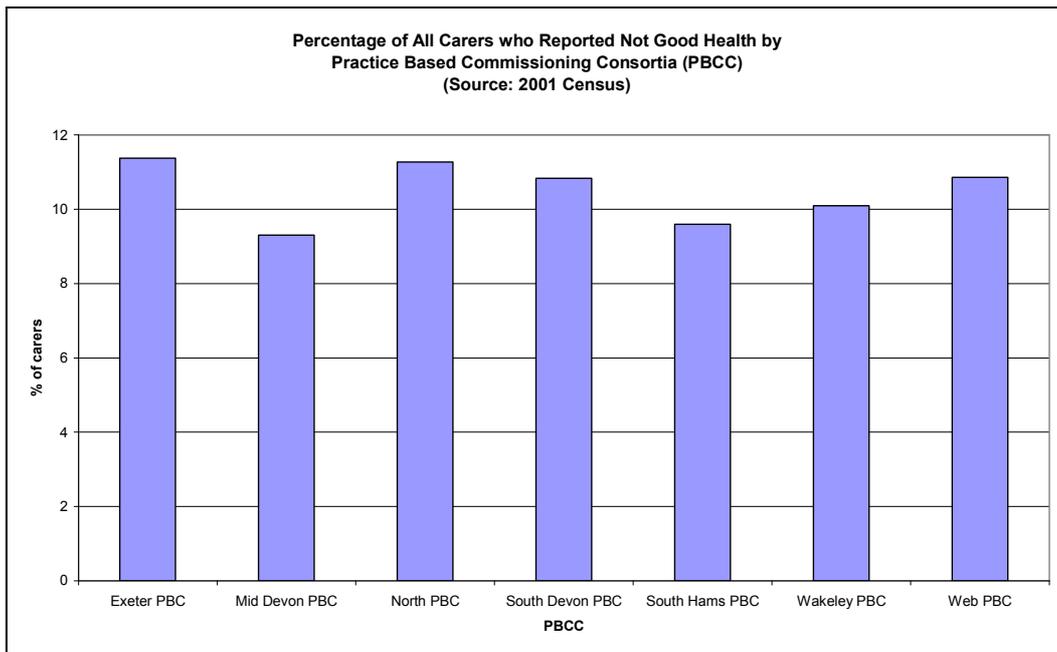
7.12 Figure 12 below shows the percentage of carers in Devon reporting not good health by age group. Nearly one in five of those aged over 75 years of age report poor health, rising to over a quarter in those aged 85 plus.

**Figure 12: Percentage of Carers in Devon Reporting Not Good Health by Age Group (Source 2001 Census)<sup>1</sup>**



7.13 The graph below (Figure 13) provides information on the percentage of carers in Devon reporting not good health by Practice Based Commissioning Consortia (PBCC). Exeter and North Devon report slightly higher percentages of those 'not in good health'. These areas mirror those areas with higher levels of deprivation.

**Figure 13: Percentage of all Carers who Reported not Good Health by Practice Based Commissioning Consortia (Source Census 2001)<sup>1</sup>**



- 7.14 Carers UK has estimated that by 2037 the number of carers is set to increase by around 60%, given our older than average population in Devon, our figures would be expected to rise by a greater percentage in the same time period.

**Figure 14: Impact on the Health of the Person Caring<sup>6</sup>**

- 47% of elderly carers report a limiting long term illness compared who 41% of people the same age in the general population
- 39% of carers reported their physical and mental health had been affected as a result of caring
- 20% reported feeling tired or had a general feeling of stress
- 17% felt short tempered
- 14% depressed or experienced disturbed sleep
- 4% had seen their GP about a health problem associated with caring

- 7.15 The number of people in Devon predicted to be suffering from dementia is expected to rise from 12,000 to 17,000 by 2021. A UK Dementia report estimated that one in 20 people over 65 and one in five over 80 are affected by dementia. 6% of carers look after someone with a mental disability including dementia<sup>6</sup>. This increased burden of disease will impact on the number of people who have a caring role and it is important to ensure flexible breaks (day and overnight) and other support services are easily available to avoid unplanned admissions.
- 7.16 Nationally, the impact on the mental health in women who care is significantly greater than that of non carers. If Devon is to achieve its ambition of increasing by 10% the number of people with moderate to severe dementia who are helped to remain at home by 2013, a range of support to carers including respite and emergency care will be essential.

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- 7.17 The physical demands on health including the demands of lifting and handling deteriorate more as the number of hours caring per week rises. Carers' physical health is more likely to deteriorate beyond the first year of caring. The rising prevalence of chronic illness and the drive to support people to stay in the community through self care, choice and personalised care planning will have an impact of current and future carers and their needs should be included in commissioning decisions.
- 7.18 The policy of supporting more people at the end of their life to die at home should this be their wish will have a direct effect on carers. This policy direction highlights the importance of good co-ordination of care and good support for families and carers as a minimum standard, with success measured by audits and feedback from carers on all aspects of care.
- 7.19 Overall, not surprisingly, the proportion of carers reporting that their health was affected by caring increased according to the number of hours spent per week on caring activities (see Appendix 3).
- 7.20 There is an opportunity, at local level, to develop a better mechanism to share data on carers currently held by schools, the health services, Devon County Council and the voluntary sector. Subject to a carer's consent, a central register could be developed locally to help support a shared understanding of needs and target resources to meet the needs. The Department of Work and Pensions can provide information on the proportion of people claiming carers allowance but this only includes those of working age.

## Impact on the Health of Young People

- 7.21 Young carers' health<sup>5</sup> can be severely affected by:
- caring on a daily basis and sometimes through the night
  - physical tasks such as repeated lifting and handling
  - emotional impact, anxiety, stress depression and sense of isolation
  - poor diet
  - lack of opportunity to socialise and exercise leading to an unhealthy and isolated life.

## Special Needs of Young Carers

- 7.22 Research has shown that young carers suffer from specific problems, which are different from those experienced by adults involved in caring – see Figure 15 below:

### Figure 15<sup>5</sup>: Special Needs of Young Carers

- problems with education – a lack of time for homework/exams
- isolation from other children and from family

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- lack of time for recreation
- guilt and resentment from reconciling conflicting needs of themselves and their parent
- feelings of no-one to turn to – professionals working only with the adult patient
- lack of recognition for role
- feelings of difference
- problems in the transition to adulthood (further education, finding work, accommodation, relationships)

7.23 Young carers are difficult to identify because of their silence. This silence is often the result of fear; fear of coming to the attention of professionals and fear of separation from their families either by the institutionalisation of the care recipient or by the instigation of care proceedings.

7.24 Many young carers feel stigmatised because they are different – they do not experience the same type of childhood as other children, and their parents and siblings are in some way perceived as being different. Some young carers are likely to be doubly stigmatised – those caring for parents with mental health problems or problems of addiction or siblings of someone with a learning disability. Many feel they have no-one to turn to or that they are letting people down if they talk to someone.<sup>13</sup> Schools have a key role in conjunction with health and social care professionals in providing a range of opportunities for children to seek help.

7.25 The local Safeguarding Children's Board needs to be cognisant of the needs of young carers in their work, if young carers are to achieve all the outcomes in Every Child Matters<sup>10</sup> (i.e. be healthy, stay safe, enjoy and achieve, make a positive contribution, achieve economic well-being). Training and support packages using a 'Whole Family Approach'<sup>5</sup> are being developed by Princes Royal Trust for Carers and the Children's Society funded by the Department of Children Schools and Families (DCSF). Using new key principals of practice and a Whole Family Pathway online resource, training and support packages will assist all agencies to deliver the outcomes of the new national carer's strategy<sup>7</sup> and Every Child Matters<sup>10</sup> to this vulnerable group. More information about training and publications is available from [www.youngcarer.com](http://www.youngcarer.com).

### Hidden Carers

7.26 Not all carers, whatever their age, will present themselves to public sector services. Devon County Council has supported a number of projects to improve knowledge about 'hidden' carers and provide advice and support. There is a project involving a minority group, i.e. Black and Minority Ethnic (BME), led by Hikmat piloting outreach work with Black and Minority Ethnic carers.

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<sup>13</sup> Working with carers :guidelines for good practice Committee on community care, British Medical Association (BMA) June 2007

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- 7.27 Another project funded by the Department of the Environment, Food and Rural Affairs (DEFRA) is seeking to pilot ways of reaching rurally isolated carers and providing accessible services. Early findings support the need to ensure reliable information is available to carers in rural areas. A number of projects will continue past the life of this funding such as telephone support groups, on line support groups, and training for carers.
- 7.28 In response to consultation on this health needs assessment, Devon Carers have voiced a need to include pensioners as a particularly vulnerable group.

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## 8. Health Inequalities

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- 8.1 Nationally, nearly 21% of carers providing more than 50 hours of care report that they are not in good health, compared with only 11% of the non-carer population<sup>14</sup>. However, 61% of carers in the General Household Survey (2002) claimed that their health was not affected by their caring duties (see Appendix 3).
- 8.2 The impact on the mental health in women who care is significantly greater than that of non carers<sup>14</sup>. Carers report high levels of psychological distress including anxiety, depression and loss of confidence and self esteem than non-carers. As a result of stress carers may neglect their own health (see Appendix 3).
- 8.3 Carers are a vulnerable group at a disproportionate risk of experiencing health in-equalities<sup>15</sup>.
- 8.4 Increased caring responsibilities can lead to loss of employment/ income and lead to social isolation. At present, one in five carers give up work to care and the link between poverty and poor health is well established (see paragraph 2.4). The wider economic impact of this for carers is very significant. In just one year, helping just one carer on average earnings to remain in paid work, through adequate support services and access to flexible working, contributes important amounts of tax and can stop the carer from sliding into poverty.
- 8.5 If carers do give up work, as well as the lost revenue from tax<sup>16</sup>, there would be additional costs from benefits payments, including administrative costs, and health costs for the carer. For some carers, however, the care they provide is so complex and personal that it would be extremely costly to replace. In Devon older carers of pension age of children or their adult children say that they feel they are discriminated against because they were carers before 1972 when the ruling came in giving allowance of pension points for their caring role. This has affected pensioners who might not have been able to work for several years but no allowance has been given.

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<sup>14</sup> In Poor Health: The Impact of Caring on Health, Carers UK 2004.

<sup>15</sup> Health –in-equalities: progress and next steps Department of Health June 2008

<sup>16</sup> Carers UK, Valuing Carers - Calculating the value of unpaid care, Dr. Lisa Buckner and Prof. Sue Yeandle, University of Leeds, Sept 2007

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- 8.6 The main carer's benefit, Carer's Allowance, remains the lowest benefit of its kind at only £48.65 per week (2007-08 levels) for providing at least 35 hours of care. It is lower than any other working age benefit, such as Jobseeker's Allowance and Incapacity Benefit. Not only does this drive carers into poverty, it also underlines the discrimination that they feel and experience in society.
- 8.7 The national definition and eligibility of Carer's Allowance (CA) is a non-contributory benefit for people:
- who look after a severely disabled person for at least 35 hours a week
  - who are not gainfully employed
  - who are aged 16 or over and not in full-time education.
- 8.8 The data set is based on all claims (ie 100% processing of records) so is not subject to sampling error. Figure 16 below gives the proportion of the total population claiming Carers Allowance in Devon and England over a four year period. There is no statistically significant difference in these figures and figures for 2008 are not available as the year is not complete.

**Figure 16: The Proportion of the Total Population Claiming Carers Allowance in Devon and England over a Four-Year Period**

	2004	2005	2006	2007
<b>Devon</b>	0.6%	0.6%	0.7%	0.7%
<b>England</b>	0.7%	0.7%	0.7%	0.8%

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## 9. Evidence of Effectiveness

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### Research

- 9.1 Research has shown that even quite small investments in support for carers – providing them with good quality information, offering breaks (including planned overnight respite away from the family home) and sitting services, providing practical support and training to enable them to care safely (eg to ensure they have correct guidance in lifting and handling a physically disabled person) – can make a huge difference to their everyday lives.
- 9.2 Forthcoming research by the University of Leeds, due to be published by Carers UK, will also demonstrate the critical role that better care services can make in supporting carers to stay in work. At present, one in five carers give up work to care and the link between poverty and poor health is well established.
- 9.3 Research commitments outlined within the national 10 year strategy<sup>7</sup> include:
- pilot models of best practice to improve joined up service provision between the National Health Service (NHS), Local Authorities (LA) and the third sector

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- pilots to improve the support offered by GPs for carers
- pilot annual health checks
- increase support for young carers via universal services and improved support to families
- flexible employment/caring opportunities.

## **Carers Support Workers in General Practitioners Surgeries**

- 9.4 An evaluation by Manchester Personal Social Services Research Unit (PSSRU) of Carers Support Workers (CSW) in General Practitioners (GPs) surgeries in Torbay used the general health questionnaire. Results, although not formally published, showed a highly significant reduction in distress amongst carers during the time they received services from a Carers Support Worker, and there were reductions in presence of psychiatric disorders, improvements in concentration and reductions in sleeplessness. This evaluation has informed Government policy<sup>5</sup>.

## **National Institute for Health and Clinical Excellence (NICE) Clinical Guidelines**

- 9.5 Devon Primary Care Trust (PCT) is committed to ensuring that there is a systematic process for planning, implementing, monitoring and evaluating National Institute for Health and Clinical Excellence guidelines. The Primary Care Trust accepts that National Institute for Health and Clinical Excellence guidance represents good clinical practice and effective use of resources. The process includes the commissioning and the provider arms of the Primary Care Trust.
- 9.6 Clinical guidelines pertinent to improving health and quality of life for carers include:
- National Institute for Health and Clinical Excellence guideline 42 Nov 2006 Dementia supporting people with dementia and their carers in health and social care
  - guidance on cancer services- improving supportive and palliative care for adults with cancer; National Institute for Health and Clinical Excellence National Institute for Health and Clinical Excellence March 2004
  - National Clinical Practice Guidelines (Number 23) Management of Depression in Primary and Secondary Care.

## **National Service Frameworks (NSFs)**

- 9.7 National Service Frameworks (NSFs) are evidenced based long-term strategies for improving specific areas of care. They set national standards, identify key interventions and put in place agreed time scales for implementation. There are a number of National Service Frameworks covering the major causes of ill health and mortality. There are National

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Service Frameworks covering long-term conditions including neurological conditions, mental health and more recently a plan to address palliative care (see Figure 2).

- 9.8 When implementing these frameworks locally commissioners and providers must ensure that the needs of carers are considered and those eligible for assessments are assessed and supported to have their identified needs met.

## Special Interest Groups

- 9.9 Carers UK - [www.carersuk.org](http://www.carersuk.org) Carers UK improves carers' lives through research, information provision and campaigning. Their website provides a range of information and guidelines including financial help, practical help and help in combining caring with employment.
- 9.10 The Princess Royal Trust for Carers<sup>4</sup> with the Royal college of Psychiatrists has produced a series of leaflets for mental health professionals to promote information sharing under the banner Partners in Care. These leaflets contain useful information about mental health conditions for carers as well as useful suggestions for all health professionals. They can be found at [www.partnersincare.co.uk](http://www.partnersincare.co.uk).
- 9.11 The Foundation for People with Learning Disabilities - [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk) has published useful good practice guidelines in supporting older family carers of people with learning difficulties.
- 9.12 Most chronic disease specialist web sites will include information and advice for carers.

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## 10. Current Commissioning

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### Adult Health and Social Care

- 10.1 Devon County Council (DCC) and Devon Primary care Trust (PCT) have agreed to develop and implement a Joint Strategic Commissioning Framework for carers, linked to a joint strategic review with the NHS that is inclusive and reflects the diversity of carers in Devon. A new joint strategic commissioning manager has been appointed to lead this work and will take up the post in December 2008. An interim post holder has been in place on a part time basis.
- 10.2 The post has been created to lead and manage the joint strategic planning and commissioning of services and support for carers across Devon Adult and Community Services (ACS) and Devon Primary Care Trust. Joint funding arrangements have been agreed. The post will be key in driving forward strategic commissioning across both organisations and the voluntary sector and support modernisation including the development and delivery of effective and efficient policy, practice and service redesign based on the rigorous assessment of needs and national and local best practice. The post holder will manage staff relevant to carers' services, will work closely with carers in Devon and provide direct support to the Assistant Director for joint commissioning.

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- 10.3 The current budget to support carers work (including an additional allocation in 2007-08 for emergency respite care) is shown in Figure 17.

**Figure 17: Budget to Support Carers Work (including an additional allocation in 2007/08 for emergency respite care)**

Year	2007/08	2008/9	2009/10	2010/11
Allocation	£2.802m	£3.155m	£3.402m	£3.654m

- 10.4 Current work streams include:

- emergency alert card and contingency planning - a one year project initially targeting older carers
- identification of carers through GP practices – this is a one year project to deliver four pilots in Devon
- promotion and communication of support for carers – targeting hard to reach groups including young and working carers
- carers employment – reviewing Devon County Council policies awareness and training
- Carers Involvement Framework - improving the involvement and empowerment of carers in health and social care (Appendix 4).

### Primary Care

- 10.5 The Quality and Outcomes Framework (QOF) was first introduced as part of the GP contract in 2004. It provides pay incentives to GPs when they meet certain criteria. Three Quality and Outcomes Framework points relate to carers: “the practice has a protocol for the identification of carers and a mechanism for the referral of carers for social services assessment.
- 10.6 More needs to be done to ensure this is an outcome rather than a process-driven measure. Practices can decide whether or not to pursue Quality and Outcomes Framework points as part of the national GP contract. In Devon, 97 of the 106 practices are claiming Quality and Outcomes Framework points related to carers. Unfortunately, the current national requirements do not require practices to provide routine reports that might support a health needs assessment (Appendix 5).
- 10.7 In Devon, a request is due to be put to the Primary Care Trust GP data advisory group to seek support on identifying an absolute count of patients known to GPs using a number of Read codes including: 918A, 918G, 918a – 918d, 918W, 918X and 918Y (Read codes are the recommended national standard coding system in General Practice for recording clinical information). It is recognised that this exercise will not identify everyone and would therefore only provide an estimate of those people who might benefit from an assessment and care plan. Primary care does have a key role in reducing health inequalities and has the ability to recognise the strain on carers (physical, mental, isolation and poverty) and signpost to them support and advice.

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- 10.8 When trying to establish a baseline of the number of carers per practice a report by the Royal College of General Practitioners and the Princess Royal Trust for Carers<sup>4</sup> Trust has provided a simple calculation (see Figure 18).

**Figure 18: Baseline Estimate of Number of Carers per Practice<sup>5</sup>**

Practice population	Likely number of carers	Number caring for 20 plus hours per week	Number caring for 50 plus hours per week
2,000	200	68	44
6,000	600	204	132

### Secondary care:

- 10.9 Studies have identified concerns raised by carers about the lack of recognition of their role by professionals in hospital. Carers need to be involved in discharge planning so assumptions are not made about their ability and willingness to care.
- 10.10 Carers also have unique knowledge and skills about the person they care for and can help professionals in assisting with communication and understanding of the patients' needs and problems. This is particularly important when the patients themselves have communication difficulties, as in the case of dementia and people with more severe and profound learning disabilities.

### Third Sector

- 10.11 The voluntary sector has a key role in identifying, assessing and supporting carers of all ages. Figure 19 below provides information as at 32/11/08 on data currently collected by the voluntary sector, with text following the table explaining how the data is to be interpreted.

**Figure 19: Devon Carers and Cared For Disabilities Totals**

	Total Carers	Total Cared for	Physical Disability	Hearing Loss	Substance Misuse	Dementia	Learning Disability	Visual Loss	Mental Health	HIV/AIDS	Elderly Frail	Terminally Ill
<b>East Devon</b>	880	956	473	149	3	135	146	114	155	1	366	38
<b>Exeter</b>	766	852	486	184	13	113	157	146	133	1	280	24
<b>North Devon</b>	990	1069	603	242	10	172	228	167	191	0	323	31
<b>South Hams</b>	604	642	347	135	10	118	124	98	106	0	224	22
<b>Teignbridge</b>	896	954	540	206	14	142	175	152	185	0	310	27
<b>Mid Devon</b>	833	920	485	121	14	130	137	89	168	1	240	24
<b>Total</b>	<b>4969</b>	<b>5393</b>	<b>2934</b>	<b>1037</b>	<b>64</b>	<b>810</b>	<b>967</b>	<b>766</b>	<b>938</b>	<b>3</b>	<b>1743</b>	<b>166</b>

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- 10.12 The 'Total Carers' column contains the latest totals for each Carers Link scheme in Devon. The 'Total Cared for' will be low for East Devon and Unite (Mid Devon) as this data was not captured before the database was converted.
- 10.13 The totals for each disability will not equal the real number of cared for people with this disability; this is because the form and the database allows cared for people to have more than one disability ticked. An individual cared for person could be counted in more than one disability section and this means that the disability totals are higher than the number of cared for people.
- 10.14 Appendix 6 of the report provides details of the data (NI135) collected and sent on nationally in relation to the key outcome for carers contained in all Local Authorities Performance Assessment Frameworks (PAFs) and in World Class Commissioning 'vital signs'.
- 10.15 There would seem to be a real opportunity and benefit locally to agree across agencies as to what information could and should be shared, subject to carers' wishes, in order to develop a central register. Data held could inform an ongoing understanding of the health needs of carers and the services they need to help them in their caring role.

### **Children's Services**

- 10.16 Voluntary sector providers have been invited by the Children and Young People's Services (CYPS) commissioners to work as consortia to provide services. The Children and Young People's Services commissioners have £240,000 to support/fund the development of these services.
- 10.17 Adult Services do not commit any funding or support to these services and this is something that Children and Young People's Services commissioners wish to address. The current providers work with roughly 1200 young carers across Devon, but this has been historically inequitable. The idea of the consortia is to continue with providers who know their local networks well but to bring some Devon-wide equity to recording and also to be able to develop the critical links with education, social care and also adult services. At present there is little overlap with Primary Care Trust support, although the Children and Young People's Services commissioners have been developing the strategy to ensure this happens in the future.
- 10.18 The Devon Carers Grant also supports Parent Carer Voice (PCV) contracted out to Torridge Carers in North Devon. They employ development workers for northern, southern and eastern Devon to support parent carers. This includes facilitating locality forums with parent carer chairs, promoting the service and raising awareness about the issues parent carers face. The locality chairs (6) make up a county forum which meets bi-monthly to discuss current development of services for children with additional needs across Devon.

### **Local Partnerships**

- 10.19 Currently there is a mix of local and county-wide groups and their work needs to inform the work of the Joint Strategic Commissioning Manager.

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10.20 In Devon, there are a number of carers groups (county-wide and local - see Appendix 4). Membership includes carers and representatives from Social Services and the Primary Care Trust, and carers' development/support workers. The aim of the county-wide forum working in partnership with carers is to:

- tackle issues that impact on the health and wellbeing of carers
- empower carers to play a part in shaping, monitoring and reviewing services
- ensure mainstream services recognise and meet the needs of carers
- report on progress to the Devon Health and Wellbeing partnership.

10.21 Service specific groups include:

- older people /disability
- learning disability
- mental health
- parent carers
- young carers.

10.22 A carer's involvement strategic framework is currently being reviewed and a draft schematic diagram is attached (see Appendix 4).

## **What do Carers say they want/need?**

10.23 An extract from good practice guidelines for general practitioners produced by the BMA<sup>13</sup> in June 2007 would suggest the following:

### **Figure 20: What Carers say they want/need?<sup>13</sup>**

- someone to talk to
- personalised information perhaps to include training
- opportunities for a break
- receipt of reliable satisfactory services
- recognition of their role
- care for their own health

10.24 Chairs of the local carers' forum in Devon have offered useful comments on the draft health needs assessment during the period of consultation (17<sup>th</sup>

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November to 5<sup>th</sup> December 2008) and their comments have informed the final report.

- 10.25 Work is currently taking place to review and improve the way carers are involved in the development of services, policy and strategy in a meaningful way. Carers in Devon have stated that they want to be part of developing and consulting from the start in the development, monitoring and evaluation of services. They feel there is a shortage of information about carers and their cared-for available to services, carers or voluntary/charitable providers. Current information does not bring to light the actual service needs for individuals beyond very basic factual health and social care needs. Information in a statistical form should be readily available to generic and specific carer groups who represent others or who are involved in running groups.
- 10.26 Within 'New Break' provision (see Appendix 1), there is a strong voice in Devon for the inclusion of time with their cared-for away from the family home overnight. Under emotional support (also Appendix 1) carers in Devon are saying that there should be informed advocacy and support for carers at reviews/ meetings/paperwork/form filling/assessments and care plans. Carers are saying that they can feel and can experience intimidation and being bullied by service providers and/or commissioners. Carers in Devon are saying that they would value informed support and individual support in certain situations and that this should be available through independent advocacy/mediation. This they state is different to group support, i.e. being supported to be heard and listened to.
- 10.27 The Joint Strategic Plan for Devon<sup>2</sup> recognises the impact on carers that will occur with the increasing emphasis on care at or close to home. In recognition of this, carers' needs have been included within World Class Commissioning Outcomes and the Local Authority Performance Assessment Framework (Appendix 6). Strategic commissioning for adult carers will be led by the new Joint Strategic Commissioning Manager and it will be important to ensure there is good liaison with the commissioning lead for Children's Services in relation to young people who are carers<sup>5</sup>.

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## 11. Performance Monitoring

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- 11.1 Current measures include:
- Primary Care Quality and Outcomes Framework (QOF)
  - Performance Assessment Framework (PAF) for local authorities National Indicator 135 - carers receiving needs assessment or review and a specific carers' service, or advice and information (see Appendix 6).
- 11.2 This is also included in the Operating Framework for the NHS Vital Signs and is a key outcome related to carers within the World Class Commissioning Framework.
- 11.3 Other relevant measures within Vital Signs local action level include:

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- percentage of carers of people with a long term condition who have a carer assessment
- carers for all newly referred mental health service users have access to carer assessments by 2010
- proportion of people with depression and or anxiety disorders offered psychological therapies
- proportion of all deaths that occur at home
- adults and older people receiving direct payments and/or individual budgets per 100,000 population aged 18 and over.

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## 12. Conclusion

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- 12.1 Defining who is a carer is challenging. Many carers are reluctant to come forward and seek help from the public sector. The more hours of caring undertaken per week, the greater the negative impact on people's health and well being. Carers of all ages are therefore a vulnerable group who are at a disproportionate risk of experiencing health inequalities.
- 12.2 A commitment to a new joint strategic commissioning post has been made between Devon County Council and Devon Primary Care Trust to support more integrated strategic commissioning. More resources have come down from the centre to support carers including increased availability of flexible breaks to help them maintain good health, remain in employment should they wish or help to attain good level of education if they are still in education.
- 12.3 As the population grows and the number of people over 65 and over 75 grows the number of carers and the demands on carers will increase. The policy to support people in the community at or closer to home will also impact on carers.
- 12.4 A joint strategic action plan to underpin the ambitions outlined in the five-year strategy<sup>2</sup> has been developed (Appendix 7) but will need to be updated if all the recommendations in this report are accepted. The role of the new joint strategic commissioner working in partnership with carers will be crucial if the targets and ambitions are to be realised and the health and well-being of carers improved.
- 12.5 Proxy measures, either in the form of Vital Signs or Local Authority Performance Assessment Framework indicators, and agreed through the Local Area Agreement process, should be regularly reported to strategic leaders across Devon County Council and Devon Primary Care Trust and to carers.
- 12.6 Dr Virginia Pearson, Director of Public Health a joint appointment between Devon County Council and Devon Primary Care Trust will take this report forward.

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## 13. Acknowledgements

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- 13.1 The Public Health Directorate of Devon Primary Care Trust has led in the production of this health needs assessment carers.
- 13.2 The author of the report however, is indebted to a number of people from Devon County Council, staff from Devon Primary Care Trust and others in neighbouring areas across the south west region. All have freely given up time and offered support, advice and expertise. They are listed below:
- 13.3 Their comments have informed the final version of this report.
- Beryl Perrin
  - Chairs of Local Carer Forums
  - Clare Cotter
  - David Church
  - Gwen Pearson
  - James Drummond
  - Jennie Stephens
  - John Shaw
  - Kirsty Priestly
  - Matthew Byrne

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## 14. List of Figures

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## 15. Appendices

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# **APPENDIX 1**

## **10 Areas for Development 2008-11, as Identified in ‘Carers at the Heart of the 21<sup>st</sup> Century, Families and Communities’, (HM Government June 2008)<sup>7</sup>.**

### **2008-11 Commitments - 10 Areas for Development**

As identified in the ‘Carers at the Heart of 21<sup>st</sup> Century Families and Communities: “A Caring System on Your Side. A Life of your Own’’. (HM Government - June 2008)

#### **Information & Advice**

- every carer will be provided with the opportunity to access comprehensive information when they need to - the information will be easily accessible for all groups of carers, and specific to their locality

#### **New break provision**

- £150 million from central government for breaks from caring for carers - to be provided in a flexible way, to meet the personal needs of carers and the people that they support.
- pilots will be used to develop models of break provision to demonstrate the cost-effectiveness of breaks and to help identify what constitutes high-quality provision based on carers’ needs

#### **Expanded NHS Services**

# **APPENDIX 1**

A range of pilots to be introduced:

- to look at how the NHS can better support carers through developing models of best practice and enabling more joined-up service provision between the NHS, local authorities and the third sector
- to improve the support offered for carers
- annual health checks for carers

## **Employment and Skills**

- up to £38 million to enable carers to be better able to combine paid employment with their caring role and re-enter the job market after their caring role has ended through encouraging flexible working opportunities and increased training provision

## **Emotional Support**

- improvement of the emotional support offered by central, local government and the third sector to carers

## **Young Carers**

Over £6 million to help ensure young carers are protected from inappropriate caring and receive the broader support they need Through strengthening:

- support from universal and targeted services
- quality and join-up of support around families so children are better protected from inappropriate caring

## **Expert Partners in Care**

- training carers to enable them to strengthen them in their caring role and to empower them in their dealings with care professionals

## **Workforce**

- training professionals across the board, from health to housing, to provide better services and support for carers

## **Third Sector**

- ensure that third sector support for carers is available throughout the country to a larger proportion of carers than is currently reached

## **Information about carers**

- provide vital data about carers to aid commissioners and policy makers at a local and national level in providing better support for carers
- establishing a standard definition of carers across government

**Total investment over 2008-11: over £255 million in addition to over £22 million previously committed.**

## **APPENDIX 2**

### **The Way Ahead: Five Years of Improvement, Health and Social Care in Devon 2008-2013, Carers Five years of improvement**

We intend to: Take positive action to develop our partnership with carers, enabling them to maintain a balance between caring responsibilities and a life outside caring, while ensuring the person they care for receives the best possible support.

#### **We will achieve:**

- a public health analysis of the needs of carers in Devon by 2010
- improved access to carers' assessments and care plans demonstrated by:
  - 5% year on year increase in the percentage of carers of people with a long-term condition who have a carer assessment
  - carers for all newly referred mental health service users have access to carer assessment by 2010
- increasing proportions of carers who receive a carer's break or other specific advice and information in the year following a carer's assessment until 2013
- emergency plans so that carers of people with complex needs know what will happen to the person they care for should they themselves fall ill, with all those assessed as needing and wishing this, having a plan in place by 2010

## APPENDIX 3

**How the Carer's Health has been Affected by the Number of Hours Spent Caring per Week – Carers Great Britain 2000 – ONS 2002 (General Household Survey<sup>5</sup>)**

	Number of hours spent caring per week			
	Under 20	20-49	50 more	or Total*
	%	%	%	%
Feels tired	12	34	52	20
Feels depressed	7	27	34	14
Loss of appetite	1	5	8	3
Disturbed sleep	7	24	47	14
General feeling of strain	14	35	40	20
Physical strain	3	10	24	7
Short tempered	11	29	36	17
Had to see own GP	2	8	17	4
Other	2	4	2	2
Health not affected	72	39	28	61
<i>Weighted base (000's) = 100%</i>	<i>4,798</i>	<i>1,086</i>	<i>713</i>	<i>6,672</i>
<i>Unweighted sample</i>	<i>1656</i>	<i>371</i>	<i>249</i>	<i>2301</i>

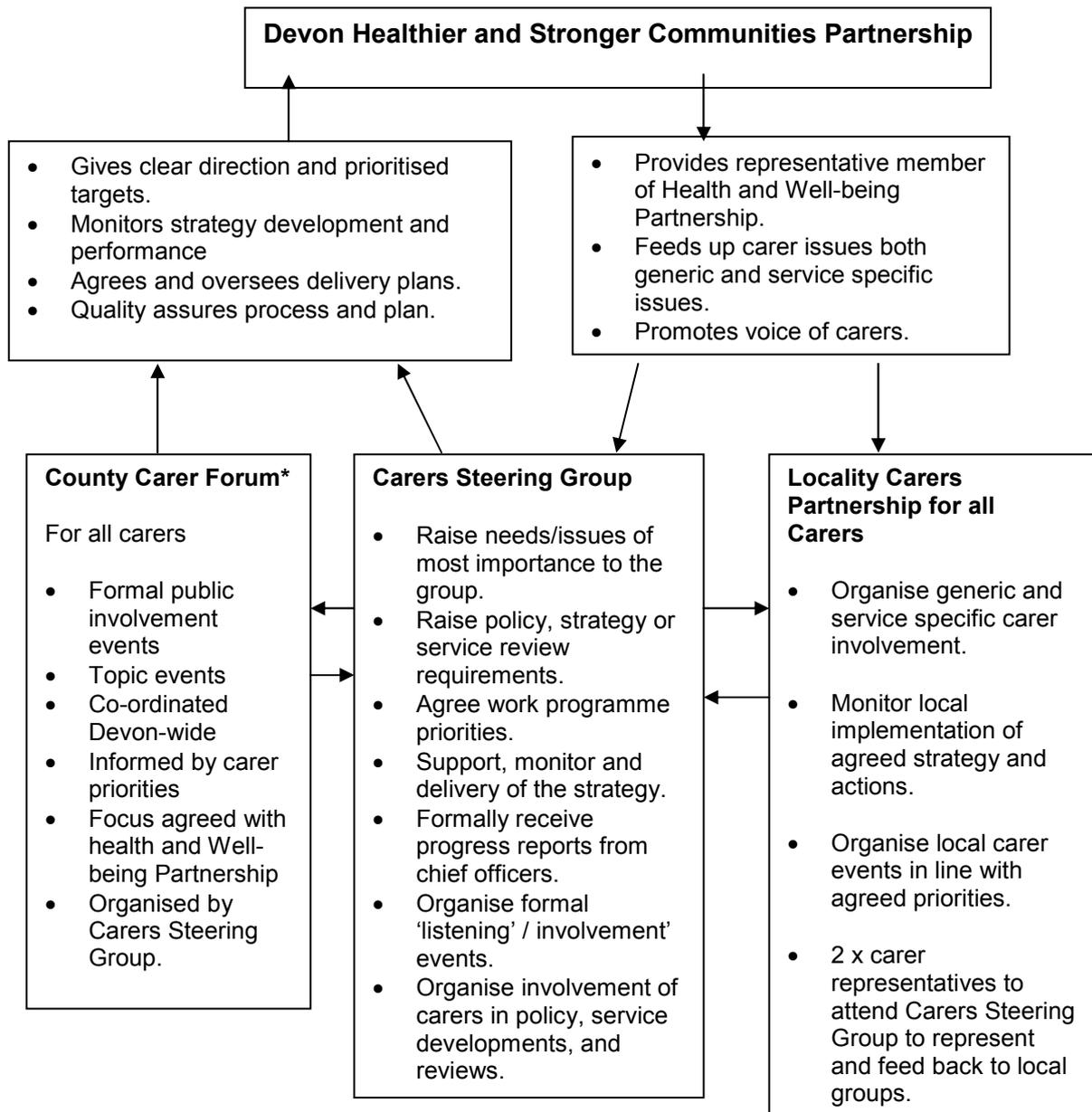
\* Total includes a few people who could not estimate the number of hours.

**How the carer's health has been affected by the number of hours spent caring per week (GHS) applied to the number of carers identified in Devon by the 2001 census (72,400)**

	Under 20 hours		20-49 hours		50 or more hours		Total	
	%	%	%	%	%	%	%	%
	% applied to % Devon carers							
Feels tired	12	6121	34	2384	52	7487	20	14484
Feels depressed	7	3571	27	1893	34	4895	14	10139
Loss of appetite	1	510	5	351	8	1152	3	2173
Disturbed sleep	7	3571	24	1683	47	6767	14	10139
General feeling of strain	14	7142	35	2454	40	5759	20	14484
Physical strain	3	1530	10	701	24	3456	7	5070
Short tempered	11	5611	29	2033	36	5183	17	12312
Had to see own GP	2	1020	8	561	17	2448	4	2897
Other	2	1020	4	280	2	288	2	1448
Health not affected	72	36729	39	2735	28	4031	61	44177

# APPENDIX 4

## Draft Carers Involvement Strategic Framework



The aim of County Carer Forum\* – working in Partnership with Carers is to:-

- Tackle issues that impact on the health and well-being of carers
- Empower carers to play a part in shaping, monitoring and reviewing services
- Ensure mainstream services recognise and meet the needs of carers
- Report on progress to the Devon Health and Well-being Partnership

\* Currently under review

## **APPENDIX 5**

### **Quality and Outcomes Framework (QOF) - Requirements Regarding Carers**

#### **Management indicator 9**

The practice has a protocol for the identification of carers and a mechanism for the referral of carers for social services assessment.

#### **Management 9.1 Practice guidance**

The practice should have a procedure for how carers are identified and a referral protocol to social services for assessment of carers support needs or to other local support such as carers centre.

A carer is defined as, someone who, without payment, provides help and support to a relative, friend or neighbour, who could not manage to stay at home without their help due to age, sickness, addiction or disability. The practice should remember to include any young carers who are particularly vulnerable.

#### **Management 9.2 Written Evidence**

The protocol is available. (Grade A)

#### **Management 9.3 Assessment Visit**

The policy is discussed.

#### **Management 9.4 Assessors' Guidance**

The assessors should enquire of various team members what action they would take when they identify that a carer may benefit from social services involvement.

#### **Further information:**

'Focus on Carers and the NHS-identifying and supporting hidden carers. Good Practice Guide' [www.carers.org/data/files/carersnhs-11.pdf](http://www.carers.org/data/files/carersnhs-11.pdf)

BMA Guidance on Working with Carers [www.bma.org.uk/ap.nsf/Content/Carers](http://www.bma.org.uk/ap.nsf/Content/Carers)

NHS Carer Information Strategies guidance – HDL22 (2006) (sections 3.3 and 3.10) [www.sehd.scot.nhs.uk/mels/HDL2006\\_22.pdf](http://www.sehd.scot.nhs.uk/mels/HDL2006_22.pdf)

Scottish Enhanced Services Programme 2007 – services for carers [www.sehd.scot.nhs.uk/publications/DC20070907sesp.doc](http://www.sehd.scot.nhs.uk/publications/DC20070907sesp.doc)

## APPENDIX 6

### Information on National Indicator (NI) 135 Carers Services - Devon

#### Historic Data

Year	No of carers receiving services	No of carers receiving information and advice only	Total clients receiving a community based service in the year (P2f)	PAF C62	NI 135
2004/05	1190	708	21307	5.59%	8.91%
2005/06	4499	2613	22921	19.63%	31.05%
2006/07	4024	2632	22887	17.58%	29.08%
2007/08	4257	1703	23730	17.94%	25.11%

#### Explanation of data

**C62 definition:** The number of carers receiving a 'carer's break' or a specific carers' service as a percentage of clients receiving community based services, who were assessed or reviewed in the year.

**P2f definition:** Number of clients receiving a community based service.

**NI 135:** The number of carers receiving a 'carer's break' or a specific carers' service or information and advice as a percentage of clients receiving community based services, who were assessed or reviewed in the year.

**NB** All carers receiving a service must also have been assessed or reviewed in the year. This has a massive impact on the figure as we provide services and information to many carers who do not have an assessment for example the "take a break" scheme and Carer's Link.

#### Carers Data Comments

- Previous years' data was compiled from sample rather than whole population which could have caused distortions in the data and possibly inflated the numbers of carers receiving services due to the methods of collection
- The data from the Grant Funded Services and carers link does not link with the data from CareFirst so may include duplicates, as some clients may already be receipt of services from ACS.
- This would particularly affect the number of clients receiving information and advice only, as in previous years we have used the number of clients in the carer's link as the number who receive information and advice.
- Grant Funded Services data would also suffer from the same problems, with some possible duplicates included in the figure.

## APPENDIX 7

### The Way Ahead Strategy to Delivery, Section J Carers (Local Document)

#### An Outline of Our Plans:

<b>J.1 Improving understanding</b>	<b>Metric:</b> A public health analysis of the needs of carers in Devon by 2010.
	<b>Description:</b> The Annual Public Health Report 2007/08 identified that a full public health analysis should be completed to achieve a clearer understanding of the needs of carers, and how we can work to support their role as partners in care.
	<b>Action headlines:</b> <ul style="list-style-type: none"> <li>• Develop scope and plans for a full public health needs analysis relating to carers</li> <li>• Identify target groups for additional focus within this assessment including young carers, carers for people with learning disability, older carers, carers for people with mental health problems, carers for people with long term conditions or disability</li> <li>• Use information as basis for updating and further improving our plans for carers in 2010</li> </ul>
<b>J.2. Improving identification, access and plans</b>	<b>Metric:</b> Improved access to carers assessment and plans demonstrated by: 5% increase in year on year of the percentage of carers of people with a long term condition who have a carer assessment; and full access for all carers of newly referred mental health service users by 2010.
	<b>Description:</b> Range of initiatives across all carer groups to improve identification and access to services, with a specific focus on carers who are harder to reach.
	<b>Action headlines:</b> <ul style="list-style-type: none"> <li>• Improve identification through a funded 1 year pilot with four GP practices with University study of impact and appropriate roll out thereafter, with specific attention to hard to reach carers</li> <li>• Review and improve information and communication for all carers, through work with key contact points</li> <li>• Ensure identified carers have access to assessment and plans for support for their caring role</li> <li>• Improve support for working carers, initially through improved practices in Devon County Council and the NHS for our own employees.</li> </ul>

<b>J.3. Meeting carers needs</b>	<b>Metric:</b> Increase the proportion of carers who receive a carers break or other specific advice and information in the year following a carer's assessment, by 2013.
	<b>Description:</b> A focus on the quantity and quality of support for carers, and the help available to access this.
	<b>Action headlines:</b> <ul style="list-style-type: none"> <li>• Review the quantity and quality of planned short breaks available to carers in Devon, building on the existing progress.</li> <li>• Improve support for carers through GP practices, initially through the four pilots to include access to counselling and health checks</li> <li>• Development of information and referral routes for advocacy, bereavement counselling, assistance for young carers</li> </ul>
<b>J.4. Improving support at times of crisis</b>	<b>Metric:</b> Emergency plans for carers of people who have complex needs and who wish a plan by 2010.
	<b>Description:</b> Actions to address the needs of carers at times of sudden change / crisis with a robust emergency response underpinned by access to appropriate support.
	<b>Action headlines:</b> <ul style="list-style-type: none"> <li>• Develop tools and systems for a robust carers emergency response including contingency planning and information for carers at times of crisis</li> <li>• Implement alerts cards and develop effective IT links to support monitoring and implementation of these</li> <li>• Produce directory of resources in partnership with carers and carers workers to improve access to information and signposting of relevance, including in crisis situation</li> <li>• Ensure training and information for professionals who may need to deliver the emergency response</li> </ul>
<b>J.5. Recognising and working with carers as partners in care</b>	<b>Metric:</b> Evidence of carer awareness, inclusion and satisfaction through results of consultation and feedback surveys.
	<b>Description:</b> An approach that recognises carers as partners in care and fully acknowledges the important role of carers through involvement in planning and delivery of services.
	<b>Action headlines:</b> <ul style="list-style-type: none"> <li>• Agree new Carers Involvement Framework with the County Carers Forum, with initiatives that will target and support hard to reach carers</li> <li>• Highlight the importance of carers through Devon's current 'Devon Cares Campaign'</li> <li>• Promote training for professionals, and carers themselves, to ensure support for the caring role</li> <li>• As part of our Joint Strategic Needs Assessment, conduct annual consultation and feedback surveys for carers commencing in 2009/10</li> </ul>