

Newcastle JSNA: CARERS November 2008

What do we know?

- 1 in 10 people in Britain is a carer.¹
- Every day 6,000 people take on new caring responsibilities.²
- The economic value of the contribution made by carers in the UK is estimated at £87 billion per year.³

Newcastle's Carers Strategy highlights:

- Newcastle upon Tyne has around 26,000 adult carers⁴
- Carers from a black and minority ethnic (BME) background are less likely to have support due to negative assumptions and stereotypes about their cultural difficulties.
- Nearly two thirds of working age carers are juggling paid work with their caring role.
- Over half of all carers have physical and mental health problems of their own.

Facts And Figures

Provision of unpaid care

Office of National Statistics (ONS) data suggests one in ten of all adults are carers and that Newcastle upon Tyne is broadly similar to the rest of the North East and England. The data suggests that slightly more carers in Newcastle upon Tyne and the North East (25%) are providing 50 or more hours care a week than the England average of 20% (Figures 1 and 2).

Figure 1: Provision of unpaid care in Newcastle upon Tyne

All people who:		Newcastle upon Tyne MD	North East	England
provide unpaid care	Count	26,267	276,593	4,877,060
provide unpaid care: 1-19 hours a week	Count	16,390	171,753	3,347,531
provide unpaid care: 1-19 hours a week	%	62.4	62.1	68.64
provide unpaid care: 20-49 hours a week	Count	3,390	35,736	530,797
provide unpaid care: 20-49 hours a week	%	12.91	12.92	10.88

¹ Carers at the heart of 21st-century families and communities, Department of Health, 2008

² Carers at the heart of 21st-century families and communities, Department of Health, 2008

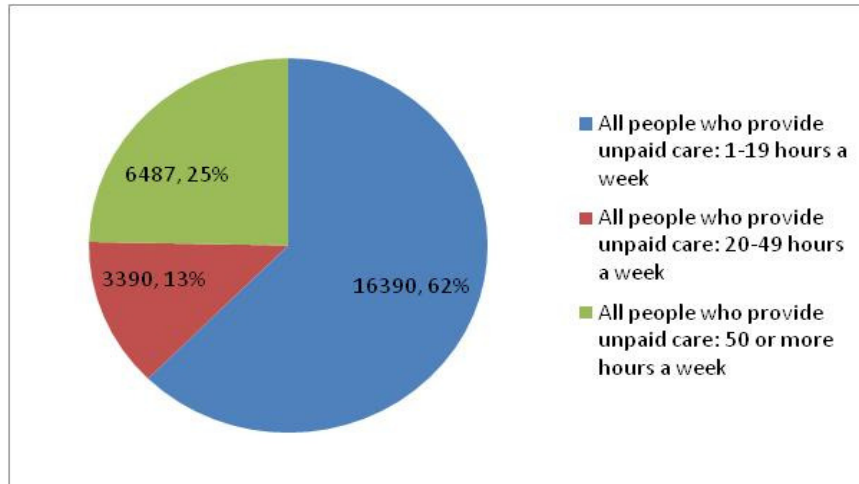
³ Valuing Carers – calculating the value of unpaid care, Carers UK, 2007

⁴ Newcastle Carers Strategy September 2005 - August 2008 (based on ONS census data, 2001)

provide unpaid care: 50 or more hours a week	Count	6,487	69,104	998,732
provide unpaid care: 50 or more hours a week	%	24.7	24.98	20.48

Source: Office for National Statistics

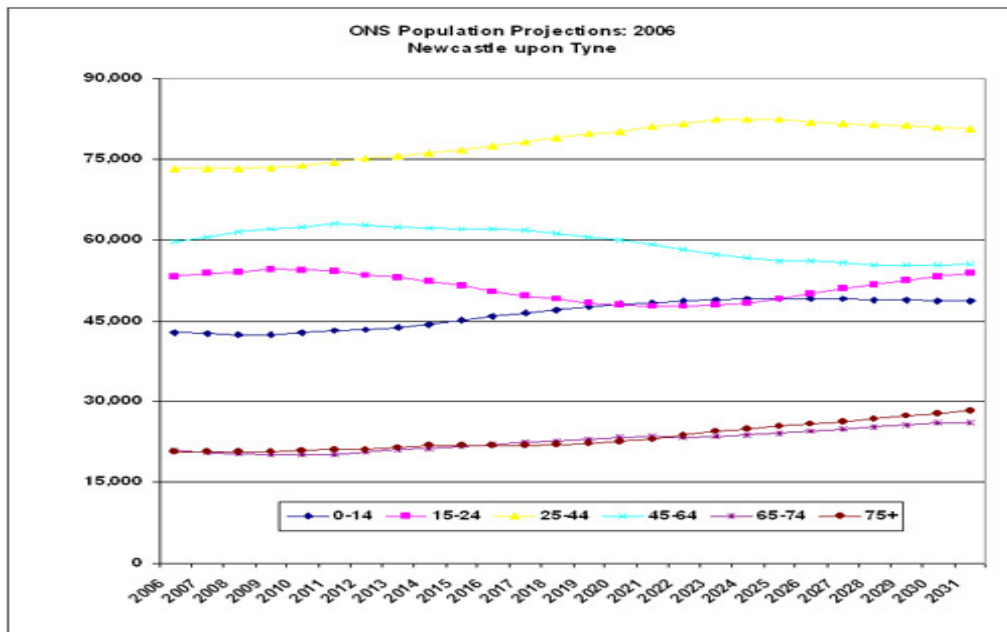
Figure 2: Proportion of all people who provide unpaid care in Newcastle upon Tyne



Source: Office for National Statistics

Provision of unpaid care for older people

Over half of all carers look after someone over 75. [ONS population predictions](#) for Newcastle upon Tyne predicts a growth in the proportion of the population aged over 65 based on 2006 estimates that suggests more people will be providing unpaid care year on year.



Provision of unpaid care for people with limiting long-term illness

In 1991, just under 29% of households in Newcastle upon Tyne had one or more persons with a limiting long-term illness. By 2001, this had increased to just over 39%. Newcastle has increasing numbers of people with complex physical and learning disabilities living longer, with increased expectations in relation to levels of support to enable independent living. At present we estimate there to be 1,449 adults with learning disabilities in Newcastle and 418 children. National predictions suggest that the number of people with learning disabilities will rise by 1% a year for the next fifteen years and we expect this increase to be reflected in Newcastle upon Tyne.⁵

Provision of unpaid care by older people

Older carers are some of the poorest people in the UK and are most likely to be managing alone. Approximately 13% of carers in Newcastle upon Tyne are aged 60 and over, which is in line with 14% across England (Table A).⁶

Table A. People aged 60 or over who provide unpaid care and percentage of people aged 60 or over who claim pension credit

Area	Men			Women			All Carers %	Pension Credit claimants %	Carer's Addition claimants %
	60+	Carers	%	60+	Carers	%			
UK									
England	4,363,689	614,991	14.1	5,471,082	701,163	12.8	13.4	21.5	
Northern Ireland	123,128	14,504	11.8	160,492	18,713	11.7	11.7	30.4	
Scotland	438,332	48,552	11.1	586,785	61,559	10.5	10.7	25.6	
Wales	280,773	44,318	15.8	353,754	49,063	13.9	14.7	23.4	
Tyne and Wear (Met County)									
Gateshead	18,585	2,595	14.0	23,692	3,097	13.1	13.5	31.1	2.1
Newcastle upon Tyne	21,742	2,978	13.7	29,336	3,702	12.6	13.1	31.2	2.6
North Tyneside	18,293	2,586	14.1	24,147	3,040	12.6	13.3	28.3	1.4
South Tyneside	14,902	1,849	12.4	19,109	2,271	11.9	12.1	32.6	2.0
Sunderland	24,691	3,488	14.1	31,204	4,081	13.1	13.5	33.0	2.5

Source: DWP & NISRA 2005. 2001 Census Crown Copyright 2003

Provision of care by young people

The Newcastle [Young Carers Strategy](#) (2007) assesses the likely number of young carers based on a number of sources and concludes that reliable figures for young carers in Newcastle upon Tyne do not exist but that a low estimate (based on all the national sources) would be around 1,200 and a high estimate around 2,000.⁷

Provision of care for people with drug and alcohol problems

It is difficult to provide estimates of those caring for people with drug and alcohol problems. However, the [Hidden Harm](#) (2003) inquiry estimated there are between 250,000 and 350,000 children of problem drug users in the UK.⁸

⁵ Newcastle Partnership's Sustainable Community Strategy and Local Area Agreement, 2008

⁶ Older Carers in the UK, Carers UK, 2005

⁷ Newcastle Young Carers Strategy, March 2007

⁸ Hidden Harm – Responding to the needs of children of problem drug users, Home Office, 2003

Trends

Carers UK (2001)⁹ estimated that:

- In any one year 610,000 people become carers, equivalent to a 6.6% chance
- Women have a 50:50 likelihood of having substantial caring responsibilities before they are 59. Men reach this point at 79.
- Based on mid 2000 population estimates they suggest that, over the next 30 years, the population aged over 65 will rise from 17% to 24% with an additional three million people aged over 75.

Targets

National indicators

NI 135 - Carers receiving needs assessment or review and a specific carer's service, or advice and information

NI 136 and Vital Sign VSC03 - People supported to live independently through social services

LAA Priority objectives	Measured by	Baseline	2008/09 target	2009/10 target	2010/11 target	Lead delivery partnership
9. Ensuring adults and older people and carers access a range of services which enable them to stay physically, mentally and emotionally healthy	NI 136 People supported to live independently through social services (all ages) (*35 target LAA)	3,110 (200708)	3,130	3,150	3,160 ¹⁰	Health, Well-being and Sport

Source: Newcastle Partnership's Sustainable Community Strategy and Local Area Agreement, 2008

Performance

Information on performance measured through consultation with carers is included under the local views section.

Performance against the priority objectives of the Local Area Agreement are shown below:

Figure 6: NI 136 - People supported to live independently through social services (all ages)		
Year		Actual Outturn
2007/8	Quarter 1	3,024.7

⁹ ... It could be you - a report on the chances of becoming a carer – summary, Carers UK, 2001

¹⁰ Note: draft targets for NI 136 are based on the new calculation (not lifted directly from previous 'CAF' indicator figures and trends) – the targets are therefore estimated from the newly calculated baseline and may be reviewed at first annual refresh.

	Quarter 2	2,997.4
Source: Newcastle City Council		

Local Views

Carers' Surveys¹¹

Carers are surveyed as part of an annual survey of Social Services Department Older (aged 65 and above) Home Care Service users. The [2007](#) and [2008](#) reports are available on the Newcastle City Council website.

The findings are similar across both years with about 20% of forms returned. However, as the number of carers associated with those service users is unknown, the reports state that a response rate could not be calculated:

- In 2007, 50% of respondents were unknown to Newcastle City Council as carers. By 2008 this dropped to 26%. This suggests that the 2007 aim of reaching more carers may have succeeded.
- Most respondents were providing ten or fewer hours care per week. About 40% in both years were providing over 50 hours, which contrast to the ONS data presented in Figure 1.
- Nearly 90% of respondents care for only one person and the most common support they provided was shopping.
- Respondents were generally positive about the quality of their life, felt appreciated and that they had the right skills to care and that they would not benefit from training.
- However, less than half (48%) of respondents felt they got sufficient breaks from caring, and more than half (53%) would like to have more time to themselves.
- The majority of respondents found Home Care to be helpful; additional support most commonly came from family or friends.
- In 2007, 17% of respondents (30 people) had had contact with the Carers' Centre Newcastle. By 2008 this had risen to 36% of respondents (63 people) who had heard of the centre,
- The majority of respondents (around 70% in both years) said that they had not been told what a Carer's Needs Assessment is. Of those who had had one (about 29 in 2007, 21 in 2008) most (74% in 2007, 50% in 2008) were satisfied with the outcome.
- The typical respondent was a White British female aged over 50, often with a long-term disability or infirmity herself.

Carers Short Break Group Survey¹²

The 'Providing a Break' Group, which was a sub-group of the Carers Strategy Group specifically sought carer's views on respite care in 2006. The survey achieved a 19% response rate and the key findings were:

¹¹ Carers' Survey 2006/7 and 2007/08 (Performance and Improvement Unit), Newcastle City Council, May 2007 and May 2008

¹² Carers Short Break Group Survey, Newcastle Carers Centre, 2006

- The majority of respondents were providing care at home.
- Over half (59%) knew about Carers Needs Assessments only 26% of those who responded had actually had one carried out by Social Services. As offering separate carers assessments to carers who provide (or intend to provide) regular and substantial care is a key requirement under the Carers Equal Opportunities Act 2004, it was an area of concern to the group.
- 46% could not work because of their caring role, 27% could not have a holiday, and 22% did not get an unbroken night's sleep.
- 62% of respondents felt that both their physical and emotional health is affected by their caring role.
- Carers were asked to rank their preferences from a given list in order of preference. The most favoured first choice option (30%) was to be able to have 1 to 2 weeks annual holiday away from the cared for person/s. However, two similar options of 2 to 3 hours of a 'sitting service' in either in their own home or in a day centre (daily or weekly) jointly accounted for 44% of Carers' first choice options.

Your Views Count Survey¹³

The Carers Strategy Group included representatives from statutory agencies, carers and voluntary agencies in the city. A survey Your Views Count, of carers' experiences and views of information for carers in Newcastle upon Tyne was carried out in 2006 by the 'To be fully informed' sub-group of the Carers Strategy Group. A questionnaire was circulated to 2,073 adult carers across Newcastle upon Tyne via the groups represented on the sub-group. 432 completed questionnaires were returned and analysed. These included stroke carers, dementia carers, parent carers and carers of people with drug and alcohol problems. The typical respondent was female, aged 65 or over who had been a carer for between 8 and 16 years.

The results cover what sort of information carers want and seek, where they seek it, where they find it and how they feel it could improve. In summary the report concludes:

- The Carers Centre Newcastle is a key point of contact along with a range of other voluntary organisations and health care providers.
- However, carers experience some difficulties in accessing information, in particular, that there is too much information that is badly presented and that there is no-one to talk it through with. Carers commented that workers who provide them with information are not always sensitive to their needs and don't take the time to explain the information they are giving.
- 70% of people who said they found it easy to access information were most likely to seek out information about benefits, health issues and support groups. People were less likely to seek out information about employment or childcare. This could be more a reflection of the age range of the people who responded.

¹³ Newcastle Carers Strategy - 'Your Views Count': A survey of carers' experiences and views of information for carers in Newcastle, 2006

- Carers like written information that is clear and jargon free. Most importantly they want the opportunity to talk to someone face-to-face or over the telephone, a small number are using e-mail.
- When asked where else they would like to see information, the Post Office and supermarkets were the favourites, although carers would like to see information made available in a wide variety of places.
- The carers who took part were mainly older, female and had been in a caring role for a number of years, suggesting that access to information remains very important throughout their years of being a carer.

The report makes four recommendations:

- Greater co-ordination between information providers would reduce duplication and improve access to information for carers.
- The content of any carers' information should take into consideration the kinds of information they find most useful i.e. benefits, support groups and health issues.
- Information for carers should be clear, easy to read and follow accessible information guidelines. Wherever possible, carers should be given the option to receive information face-to-face.
- Information for carers should be accessible in public places, in particular, Post Offices, supermarkets and bus stops.

National and local strategies

National policy

The New Deal for Carers (2006) provides a number of opportunities:

1. **A national information helpline and website, which will be launched in spring 2009.** Through one telephone number carers will access all the information they need directly, or be referred onto more appropriate support;
2. A training programme for carers called Caring with Confidence, which will inform carers of their rights and the services available to them and help develop their advocacy and networking skills. The training will be available on a face-to face basis from August 2008, and on a distance learning basis, from December 2008;
3. **£25 million additional funding per year has been made available** to councils in England to provide emergency care cover;
4. **A major review of the 1999 Carers' Strategy.** This was completed and published in June 2008 entitled '[*Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own*](#)'¹⁴ It offers a vision that by 2018:

¹⁴ Carers at the heart of 21st-century families and communities, Department of Health, 2008

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

Local policy

[Newcastle's Carers Strategy 2005-2008](#)¹⁵ set out a vision for the future and action plan for change. Particular achievements to date include:

- The development of strategies or action plans for specific groups of carers: a multi-agency Young Carers Strategy developed and an action plan for the development of support to carers of people who use drugs and alcohol.
- Work on publicity and information e.g. a Young Carers Guide and carers pack
- A number of support posts: three workers at the Carers Centre, a development worker to work with older carers of adults with learning disabilities, two young carers workers. There are also five volunteer trained counsellors at the Carers Centre.
- The addition of two Welfare Rights workers and estimate that the annual benefits gain for carers was £493,601 and £85,745 gained in backdated benefits in 2006/2007. In addition the Welfare Rights service runs take-up campaigns, e.g. in GP surgeries to increase the number of carers who benefit from the service.
- Specific support: health care checks for carers piloted during Carers Week, complementary therapy (relaxation, head massage, other) available at the Carers Centre.
- Work on providing direct support (mapping of short breaks provision) and financial support (a member of the Direct Payments Team joined the 'Providing a Break' group to strengthen work around carers and direct payments).
- A number of training initiatives for carers e.g. a pilot of the course 'Looking after me' as part of the Expert Patients Programme and 'Involved and Equal' a generic training course to enable carers to develop confidence and skills in representation and negotiation.

The [Newcastle Carers Strategy Action Plan September 2008- August 2009](#) has recently been agreed and includes the following priorities:

1. Work on the Carers Information Pack is under development with plans for a draft pack to be produced by early 2009

¹⁵ Newcastle Carers Strategy September 2005 - August 2008, Newcastle City Council

2. Planning to start in 2009 for a workshop to look at employment issues and needs.
3. Map existing work to support carers from black and minority ethnic (BME) communities in 2009.
4. Developing a new carers assessment tool by November 2008.
5. Develop a dedicated Adult Services Carers Social Work Team to carry out separate carers assessments and social work intervention with carers and work in partnership with other social work teams in Adult Services and Northumberland Tyne and Wear NHS Trust adult secondary mental health services.
6. Develop an emergency card scheme for carers.
7. Develop the use of the Adult Services Carers Training Fund by gathering information from other LAs about their use of training funds and developing a strategy for the use of the fund.
8. Hold a Carers Conference planned to be held in or near Carers Week (June 2009) to inform the next 3 year Carers Strategy.

Newcastle City Council's [Social Inclusion Strategy](#) (2008-2011) sets the government's social inclusion priorities in a local context. It identifies nine priority groups as either most socially excluded or most in danger of social exclusion. This includes:

- Adults and young people who face exclusion because they are carers.¹⁶

Newcastle upon Tyne's [Local Area Agreement](#) represents the short-term delivery plan of the longer-term Sustainable Community Strategy. This includes a summary list of all priority objectives for improvement in Newcastle including:

- Ensuring adults and older people and carers access a range of services which enable them to stay physically, mentally and emotionally healthy

Current activity and services

[Carers Centre Newcastle](#) has approximately 1,053 current carers on its database and offers:

- Five trained volunteer counsellors (two are specialists in bereavement counselling).
- Mental health carer support worker runs 'drop-in' sessions.
- Three generic carer support workers.
- Signposting to information sources.
- Training and information about legal rights, benefits etc for both carers and professionals.
- Information and resources including a directory of local support groups and services
- Carers Guide for adults developed in partnership with the City Council and a multi-agency guide for young people.
- They also ran a pilot course 'Looking after me' as part of the Expert Patients Programme.

¹⁶ Building strong and inclusive communities: Newcastle City Council Social Inclusion Strategy 2008 - 2011

In February 2006, a **Young Carers Support Worker** was appointed by Newcastle Healthy Cities, with funding from Newcastle Social Services Carers Grant and seconded to Barnardos, who manage other Young Carers Services in the region. There are currently a number of Young Carers Workers at the Young Carers Project in Newcastle upon Tyne, with plans for further development of the Service. In September 2008, the number of young carers service users open to the Young Carers Project was 45. However, the Young Carers Project does a lot of awareness-raising and educating as part of a wider remit to increase the recognition and support of young carers across many sectors.

There are many voluntary sector organisations providing support to carers in Newcastle upon Tyne. A directory of services has been compiled and can be accessed through the [Patient Information Centre](#), part of Northumberland, Tyne and Wear Mental Health NHS Trust. Carers Centre Newcastle can also provide the most up-to-date information on carers organizations.

What is this telling us?

What are the key inequalities?

1. Ageing population in Newcastle upon Tyne potentially leading to more carers in the city year on year
2. Low uptake of Carers' Needs Assessments across the city
3. Poor emotional and physical health of carers reported in carer surveys
4. Low levels of engagement from carers from BME backgrounds
5. Issues regarding employment for carers due to caring responsibilities

What are the key gaps in knowledge / services?

Carers from BME backgrounds

There has been a perceived lack of success in engaging with BME community groups and thus reaching carers in the BME communities by organizations providing services for carers.

Young carers

The numbers of young carers in Newcastle upon Tyne is unknown, therefore some young people may not be accessing services

Carers Needs Assessments

Offering separate carers assessments to carers who provide (or intend to provide) regular and substantial care is a key requirement under the Carers (Equal Opportunities) Act 2004 and there is concern surrounding the uptake of this service in Newcastle upon Tyne.

Employment

46% of responders to a local survey could not work because of their caring role. Further work is needed to better understand what some of the issues are.

What are the risks of not delivering our targets?

The level of demand on health and social care services will rise – either in direct care for those with health needs or because carers have themselves become ill or disabled. There are also hidden costs in the impact of emotional and financial strain on the individual, family, community, local business and the state.

Carers UK published '[Valuing Carers](#)' – calculating the value of unpaid care (undertaken by Leeds University) in 2007 which suggests that carers now save the state £87 billion a year. This is a rise of 52% across the UK, an increase of £30 billion on the last figure of £57 billion which Carers UK published in 2002. They state that the value of this care is greater than the annual budget for the NHS (£82 billion in 2006/7).

Is what we are doing working?

The [Newcastle Carers Strategy 2005-2008](#) is broad and includes a variety of hard to reach groups including young carers, particular attempts to establish links with BME groups and carers for those with drug or alcohol problems. **Newcastle Carers Strategy Action Plan September 2008- August 2009** has been signed off to give commitment from partners involved to continuing to address carers' issues.

What is coming on the horizon?

In population terms, half of the current adult carers are caring for someone aged over 75 years and may have health problems of their own. An increase in the older population can only increase this number and the level of support needed.

The recently published national strategy - [Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own](#)¹⁷ provides opportunities to improve services and support for carers over the longer term.

What should we be doing next?

1. [Deliver the Newcastle Carers Strategy Action Plan September 2008- August 2009](#) to address key areas for development including carers from BME backgrounds, assessments, training, employment and put in place an emergency card scheme for carers as part of the national New Deal for Carers
2. Respond to the commitments outlined in the Carers at the heart of 21st-century families and communities strategy

¹⁷ Carers at the heart of 21st-century families and communities, Department of Health, 2008