

Every Carer Counts

Carers' Strategy for Leeds 2009 to 2012



the Leeds Initiative

the Leeds Initiative

Leeds Multi-Agency Carers' Strategy Implementation Group

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the Leeds Initiative

Local partnerships making things happen

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Pills!

A

Young Carer's

Life

Foreword

I am very pleased and proud to be able to present the latest Multi-Agency Carers' Strategy which is the outcome of a lot of hard work and consultation. It shows that the City Council, along with our partners in the NHS and Third Sector are really committed to increasing and improving the level and types of support that we can offer to the carers of Leeds. These are our fellow citizens who give up so much of their lives and their time to the care and the quality of life of the person for whom they care. Each year the Carers' Strategy Implementation group will be responsible for overseeing the delivery of our aims through an annual action plan.

In the Health and Social Care world we are all very aware of how much we, and the people being cared for, rely on their unpaid carers. We could not manage the care of adults and children with health or other care needs or disabilities without them. So we are committed to involving carers as partners in decisions on service planning and in the care planning of services for the person for whom they care. I feel that we have developed a good range of support services for carers in Leeds but acknowledge, too, that there is much more that can be done. The continuing increase in carers' grant funding from the Government enables us to expand these services – one example being our Carers' Emergency Plan Scheme which is being expanded and re-launched this year.

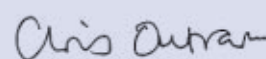
I am also pleased to say that the plans we have developed in Leeds fit very closely with the objectives of the Government's ten-year Carers' Strategy announced in June 2008 called *Carers at the Heart of 21st-Century Families and Communities*. That Strategy sets out aims and projects to support carers on a much more diverse range of issues than before, particularly relating to their work life. We look forward to working on these issues with new partner agencies such as the Department for Work and Pensions, JobcentrePlus and Carers' Advice services. The National Strategy also brings additional new funding for the next two years, most of it being directed to the NHS for more carer breaks and we will be collaborating with them and with carers to make sure it is used in ways which meet a carer's greatest need which is usually having a break and a life outside caring.

Sandie Keene
Leeds City Council, Director of Adult Social Services

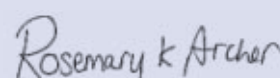
(Left) A mural created by young carers at the Willow Project representing the life of a young carer



Sandie Keene
*Leeds City Council,
Director of Adult Social Services*



Chris Outram
Chief Executive of NHS Leeds



Rosemary Archer
*Leeds City Council,
Director of Children's Services*

Introduction

In June 2008 the Government launched the National Carers' Strategy, *Carers at the Heart of 21st-Century Families and Communities: a caring system on your side, a life of your own*. This is the Government's ambitious ten-year vision that sets out the short and long term agenda for the future care and support of carers. This Strategy is based on the views and concerns of carers themselves. Over the next two years the government will provide an additional £150 million of new funding to Primary Care Trusts to work in partnership with the Local Authority to provide respite care.

The 2006 White Paper on the future provision of Adult Social and Health Care services, *Our Health, Our Care, Our Say*, committed to a 'New Deal for carers' and identified several services and issues which it will prioritise, such as a new national information service, expert carers' programme, and emergency respite services. The Government has accepted that all the ideas and aspirations outlined in *Our Health, Our Care, Our Say* cannot be achieved without new financial resources and has

announced further growth in the Carers' Grant from 2008–2011.

With the National Carers' Strategy and 2006 White Paper in mind, Leeds is launching its 4th multi-agency Carers' Strategy – the first one being launched in 1997.

A review of the 2003–2006 Carers' Strategy has revealed gaps which need to be addressed. This



Beeston Action For Families Carers Group

new Strategy document for 2009–2012 and the proposals and priorities within it have come from consultation and listening events with carers during 2005 and 2006. An average of 60–70 carers attended each year. Carers were asked to identify things that helped them and highlight things that could be improved. Workshops have also been held with young carers and parent carers.

This new Carers' Strategy sits within the context of the Leeds Strategic Plan and Local Area Agreement and the NHS Leeds Strategy. These complementary documents identify key priorities for the city that directly impact on people's health and well being and also address the wider determinants of health. Work to deliver these strategic priorities will assist in delivering the aspirations of this Carers' Strategy. At the same time work to deliver the commitments in this Strategy will contribute to the broader objectives for the city.

What is a carer?

A carer is someone who looks after a relative, partner or friend who, because of a mental or physical illness or old age, cannot manage without help. This includes parents or others raising a child who has an impairment. The help they provide is unpaid.

Carers can be of any age and sexuality and are found in all ethnic and faith communities. Carers themselves may be disabled and could be caring in any relationship.

Carers who are providing, or are intending to provide substantial care on a regular basis, are entitled to a carer's assessment and support, and it is the duty of the Local Authority to inform carers of this right. Leeds City Council (LCC) has supported carers' organisations and has itself provided services and direct support to carers for many years. Carers tell us that the existence of a Carers' Centre in Leeds for advice information and support is greatly valued as a core service.

This service is jointly commissioned and funded by LCC and NHS Leeds.

Carers' groups will continue to be supported, though they are of interest to a relatively small number of carers. But, as an avenue for peer support and expert information, particularly in the early stages of someone caring or for carers from minority or frequently overlooked groups they have a value. This support can also be provided through courses for carers.





Background demographics

The Census 2001 provides information on carers in Leeds.

- It indicates that there were 70,446 people in Leeds (9.85%) who identified themselves as providing unpaid care. Of these:
 - 14,369 provide 50 hours or more of unpaid care per week
 - 7,631 provide between 20 and 49 hours of unpaid care per week
 - 48,446 provide up to 20 hours of unpaid care per week.
- The census also told us that there were:
 - 1,232 carers aged 0–15 years (1.74%)
 - 52,983 carers aged 16–65 years (75%)
 - 16,215 carers aged 65 years and over (23%).
- People aged 45–60 years are most likely to be carers, as a proportion of the whole population. Of the population over 50 years old in Leeds, 32% provide care at some level. Women outnumber men as carers until after age 75 years when men outnumber women as carers.
- Among carers in the age groups 75 years and over and 85 years and over half of these are providing over 50 hours of care per week. It is known that carers' own health worsens as their age increases. 13% of carers are in full time work.
- Of the 1,232 carers aged under age 16, 68 were providing 50 hours and over of care; and 108 were providing 20–49 hours of care.
- 6.29% of carers are from a Black or ethnic minority community. This percentage is lower than the population as a whole, which may indicate that people from BME community groups do not identify themselves as carers.

Aims of the Carers' Strategy for Leeds

The aim of this Strategy is to ensure that people who choose to care for their relative, partner, friend or neighbour should:

- Be valued for the contribution they make to the quality of life of the person they care for and to the social care economy.
- Be supported in their chosen role.
- Know that the care they provide can be shared with paid workers where that is appropriate and desired.
- Not have to jeopardise their career or other close family relationships through their caring role.

To achieve this, the Strategy will:

- 1 Acknowledge that all carers are individuals and will be treated with courtesy, respect and dignity having regard to their religious, ethnic, cultural, sexual orientation, disability and age related needs.*
- 2 Ensure organisations providing support to carers consider their needs alongside, but separate from, the needs of the person for whom they care.
- 3 Make available independent advice or advocacy for the carer, when difficulties arise for carers in balancing their own needs with the needs of the person cared for or with their relationship with statutory agencies.
- 4 Listen to carers' views and opinions when planning service changes and when planning care or support services for the person for whom they care.
- 5 Ensure that all carers know they have a right to a carer's assessment and how to get one, regardless of their background.
- 6 Have systems in place in statutory health and social care agencies which identify and record carers so that their special needs and circumstances can be addressed, particularly for under-represented groups of carers such as male carers, disabled carers and BME carers.
- 7 Ensure that wherever possible, carers can get a break from caring through the availability of a range of respite services and opportunities.
- 8 Empower carers by providing them with good quality information about their rights and local services for them and the person for whom they care. This will be available in a range of languages and formats and will reflect the particular cultural and social issues which affect the speakers of those languages. Effective communication will always have regard to the end users, their experiences and expectations, and recognise that 'one size' cannot 'fit all'. Interpretation services will be provided which have robust quality mechanisms in place.
- 9 Provide adequate information and training to carers about techniques, equipment and medication for the person they care for, and how to care without damaging their own physical or mental health.
- 10 Commission services to make sure that appropriate information is available in other non-NHS settings that are accessible to young carers.
- 11 Provide support to young carers to ensure that the caring tasks they take on do not interfere with their own social, emotional and educational development, and that their welfare is protected as is required under their status as a child in need in the Children Act 2004.

* 'Disabled' includes physical and sensory impairments, learning disabilities, people with long term conditions, mental health needs, many of which increase with age.



Launching an advertising campaign for carers services, Victoria Gardens

- 12 Find ways to enable carers who wish to combine work and care to do so, and encourage employers to be aware of and adopt HR policies to support the carers in their workforce.
- 13 Engage and form partnerships with any organisation in the public, community or private sector to highlight the contribution made by carers and take action to assist them in their role.
- 14 Pay particular attention to identifying and addressing any barriers that carers from BME communities may face in accessing support for themselves as carers and for the person they care for. We will ensure that access and take up of services by these groups is improving and is appropriate to the proportion of their community in the general population.
- 15 Take fully into account the fact that transport arrangements for the cared for person to access community services and health appointments has an impact on the lives and incomes of their carers. This should be fully taken into account in transport policy (public transport and education, health and social care transport).
- 16 Ensure that carers in LCC and the NHS Trusts' workforce are supported through flexible working arrangements and leave policy and that they take appropriate action to make staff aware of this support and provide opportunities for carer employees to meet for mutual support.
- 17 Work with all partners in the Carers' Strategy to establish a scheme among employers in Leeds to promote best practice in supporting carers in the workforce, working in partnership with Chambers of Commerce and other employer organisations in the city.
- 18 Carry out an ongoing assessment on the effectiveness of this Strategy through monitoring of take-up of assessments and services for carers and take steps to understand and address any under or over representation by particular groups.
- 19 Carers will have access to services providing advice and information about their benefit entitlement and other financial help, primarily through Carers Leeds and the Leeds City Council Welfare Rights Unit.

Implementation

Some of the above points are generic. Each partner organisation has indicated below how they will implement the points specific to their organisation. Each organisation also has the responsibility for developing, producing and implementing an action plan to ensure that the Strategy is implemented.

Work on these areas will be led by the Carers' Strategy Implementation Group, co-chaired by Adult Social Care and NHS Leeds. It has a membership from a broad range of organisations (including the three NHS Trusts, Carers UK, Carers Leeds, Alzheimer's Society, Leeds City Council, Barnardos and up to ten carers) who are partners in the Strategy. The group draws up and monitors an annual action plan for the implementation of the three-year Strategy.

NHS Leeds through their work plan will:

For all carers

- 1 Implement a Carers' Charter **(see Appendix I)** in partnership with other NHS partners in Leeds and Leeds City Council to raise the profile and status of carers.
- 2 Develop and implement plans, with the Local Authority, for carer breaks utilising new additional monies allocated to NHS Leeds by central government and the existing Carers' Grant to Local Authorities
- 3 Involve both adult carers and young carers in the treatment plans for the person they care for, particularly where there are learning disabilities, impaired cognition or where discussions and information may appear to be beyond their years.
- 4 Provide training and resource materials for healthcare staff on carer needs.
- 5 Designate a lead officer for carers with Director level seniority to act as 'Carer's Champion' within NHS Leeds, who will ensure carers' issues are kept at the top of the agenda and embedded in all NHS Leeds business and in Local Strategic Partnerships.
- 6 As more care is provided closer to home NHS Leeds will ensure that the needs of adult and young carers are fully addressed through involving them in the development and redesign of all care pathways.
- 7 Improve the training it provides to carers to assist them in their caring role such as 'Expert Carer' courses; 'Looking after Me', 'Caring with Confidence' and moving and handling courses.
- 8 Improve access to printed material about health conditions, access to sources of advice and information on treatment, therapies, medication and side-effects.
- 9 Support GP surgeries to provide appropriate information for carers and display and provide up to date information in its health centres – adult carers have said the best place for information about help for carers to be made available is in GP practices and health centres.
- 10 Support GP practices to use the 'Yellow Card' scheme to facilitate primary care in referral to the Carers Leeds service and ensure the scheme is adapted for appropriate referral to Willow Young Carers as well.
- 11 Support GP practices to provide information and involve carers as part of their communication and involvement plans.
- 12 Work in partnership with GPs throughout Leeds to increase the offer and take up of 'Carers' Health Check'.

13 Continue to commission, in partnership with Adult Social Care, a service to provide carer awareness training to primary care staff, and a support service to carers referred by GPs.

Young carers

- 1 Raise and promote greater awareness with primary care staff of the need to recognise and respect the important role that some young carers play in the lives and state of health of their parents or siblings.
- 2 Work with Willow Young Carers Services to make sure that appropriate information is available in other non-NHS settings.

Leeds Teaching Hospitals Trust will:

For all carers

- 1 Implement the Carer's Charter.
- 2 Provide a carers' discharge information pack with leaflets on the main carers' support agencies and services in the city.

- 3 Involve carers in the review of the Trust's discharge policy.
- 4 Clarify the relationship and respective roles of carers and Leeds Teaching Hospitals Trust (LTHT) staff during in patient stays of people with learning disabilities who are accompanied by a formal or informal carer.
- 5 Work with other Leeds NHS Trusts, to explore ways of identifying and addressing carers' needs for safe moving and handling training and information.

Parents and others caring for children

- 1 LTHT staff will meet with parent carers to identify specific problems in the discharge process and develop an action plan that will lead to improvements including the provision of guidance and advice about treatment, medicines and equipment.
- 2 Take steps to increase the provision of parent accommodation and some areas have already been identified for this within the Trust's estate.
- 3 The Trust recognises that 'grouped' appointments are beneficial for children and their



parents/carers and will continue to work with parents to meet this need wherever possible whilst acknowledging that this can be particularly difficult to achieve.

Young carers

- 1 The Trust's Nursing Strategy particularly highlights the need for staff to work in partnership with carers. We will take steps to raise awareness amongst our staff that this means carers of any age and that young carers need to be recognised.

Leeds City Council will:

For all carers

- 1 Establish a Carers' Hub as one of the components of the new equality assembly, which will be the new equality and diversity involvement and engagement mechanism, which is open to all the people of Leeds.
- 2 Building on the Carers' Emergency Plan scheme established in 2006, we will use new funding provided by central government to set up schemes which will respond to carers' emergencies by providing or arranging alternative care for the cared for person, in a range of ways. This will be suitable for the carers of children and adults and commence in 2009.
- 3 Improve out of hours access to social care services and emergency duty social care services.
- 4 Provide at least three 'Changing Places' style public toilets by 2011. (This refers to a national campaign for public toilets which are equipped to enable older children and adults to be changed in comfort by up to two carers).
- 5 Continue to improve the access to sport and leisure buildings, swimming pools and individual sport facilities by adults and children with disabilities and their families and carers.
- 6 More appropriate day activities and residential facilities will be commissioned for people



Young carers with a display of their artwork at Leeds City Art Gallery

from BME communities with specific language or cultural needs so that their carers may have more short breaks, or for longer-term placements.

- 7 As part of the Leeds Disabled People's Housing Strategy, our adaptations service and the Arms Length Management Organisations (ALMOs) will publish detailed literature explaining how adaptations to the home and disabled facilities grants are provided and how Health and Safety and Building Regulations determine what is possible. It will include timescale guidance so that carers can have realistic expectations, and can provide care in their own home safely for themselves and the person for whom they care.
- 8 Make it a contract requirement that home-based breaks providers give families a rota with named workers in advance.

- 9 Work to ensure that social care workers have better and more up to date information, materials and training about services and resources for clients so that carers can have confidence in their ability to help them.
- 10 Inform carers of their right to an assessment and to provide carers' assessments as part of the Local Authority's automatic duty – Adult Social Care has set a target of 30% of carers of adults to receive a carer's assessment by 2011.
- 11 Communication – the current carers' page on the City Council website will be improved and made interactive. We will continue to produce high quality literature and publicity, regularly revised and available in a wide range of formats and languages which reflects the diversity of Leeds' citizens.
- 12 Adult Social Care will engage with the further education sector to improve the quality of the support available to students with special needs, and remove barriers to their participation in courses.
- 13 Extend and promote Direct Payments and Individual Budgets as alternative ways of providing carers' services. We will encourage take up of Direct Payments and Individual Budgets by disabled people through their

carers. Specific information on Individual Budgets for carers will be provided.

Parents and others caring for children

- 1 Parents and carers will be involved in reviewing the existing arrangements for the transition of children with any disability from school and children's social care services to college/ community and adult social care services, and ensure that in the process the carers receive information and guidance from specialist transition workers.
- 2 We will work in partnership with parents to address their issues regarding the provision of education in schools, special educational needs assessments and therapy services. We will provide support and advocacy to parents in having their voices heard by schools and education services, through our Parent Partnership Service, and the Director of Children's Services Unit. Parents want more independent advocacy.
- 3 Using the opportunity provided by *Aiming High for Disabled Children*, we will increase and improve the availability of out-of-school child care, holiday playschemes, play and leisure



Young carers celebrate Carers Week 2008 at Leeds Art Gallery

for children with disabilities as a way of giving carers a short break.

- 4 We will continue to promote and increase the number of parent carers who use direct payments for social care services to meet their children's needs.
- 5 Improve communication of information about services and involvement in service development and change by establishing a regular, termly newsletter for parents of children with special needs.
- 6 Establish a 'core offer' of health and social care support and services for families of children who are ill or have disabilities, including regular breaks.
- 7 Increase the range and availability of short breaks for parent carers.
- 8 Through our Family Support Parenting strategy, we are committed to increasing the participation of parents and carers, and working with them to achieve the best possible outcomes for their children.

Young carers

- 1 Leeds City Council will ensure that Adult Social Care services and Children's Social Care services improve liaisons during the period when young carer becomes 18 and can no longer access the Young Carers' Service. Priority will be given to ensuring that the young carer is able to take up further education and training opportunities to ensure their future. The Willow Young Carers' Service and the Adult Carers' Support Services will also collaborate to assist in this process.
- 2 Work with Willow Young Carers to make sure that appropriate information is available in other settings used by young carers.

Leeds Partnerships Foundation Trust

We provide services to over 520,00 people who are experiencing mental distress or have a learning disability. Whilst most of these people live within

the metropolitan boundaries of Leeds, some of our specialist services accept referrals from across the UK. We operate from 48 sites and provide help for over 2,000 people every day.

We value the massive contribution that carers make in supporting the people they care for and as an organisation; we in turn will support carers by ensuring that:

- 1 We will implement a Carers' Charter in partnership with other NHS partners in Leeds and Leeds City Council to raise the profile and status of carers. This will be supported at the highest level by our organisation. We provide a wide range of information for carers. A Carers' Handbook has been developed and is available for all carers who are referred to our service. The Carers' Support Team are developing an increasing range of leaflets including an information sheet with key contact numbers. These will be available on the Trust's website.
- 2 The new website will contain a 'Carers' Page' offering support, information and key telephone numbers to carers.
- 3 Through NHS Direct and Dial House, we will, where appropriate, provide support for carers who find themselves in crisis. Carers of service users who are accessing our services either as in-patients, through acute day services, or via the crisis resolution and home treatment team will have 24-hour access to a mental health professional, via the ward staff or the 24-hour helpline. The crisis resolution and home treatment team make crisis referrals regarding carers who need support to either the appropriate care co-ordinator, or to the Carers' Support Team.
- 4 We will develop our new data system PARIS across the whole of the Trust so that we can collect accurate data about carers and which in turn will enable us to shape our services appropriately.
- 5 We work towards reducing the differential of services available to carers of older people. We will scope what is currently provided, and seek ways to expand our support services to address the imbalance for people over 65.



Carers explore their experiences with each other at Carers Leeds

- 6 Carers' Connections will provide a wide range of education programmes to support carers in their role. These courses can be accessed by individual carers through a self referral or via the Carers' Support Team. The courses cover many issues around mental health problems, medication and treatment, mental health legislation, helping carers to manage their own health.
- 7 Carers are welcomed and included in care programme meetings, and care co-ordinators are encouraged to seek out the views of carers. Where the service user is in agreement carers are consulted with and valued as an important part of the care team. Carers will be included and supported where appropriate through the care programme of the person for whom they care. Carers' needs and contributions will be captured within the care plan, and supported by the care co-ordinator.
- 8 Carers' own needs will be assessed and supported as appropriate, the care co-ordinator or carers' worker will provide support and information about respite, self-care, and access to further information. This can also be found on the Trust web site.
- 9 The Carers' Support Team will support carers in communicating with mental health professionals where family members feel they are not being heard or understood. Whilst not able to provide an independent Advocacy role they will advocate on behalf of the carer. The PALS service is also available to support carers through issues where they needed support.
- 10 As an organisation we will ensure that carers are able to make a significant contribution to the welfare of the person they care for, they are included in training, involvement opportunities, recruitment and selection, and consultations around service re-design. This is a core standard of our Involving People Policy.
- 11 The Carers' Support Team along with the practice development staff will provide specialist training for the police force, around the care and responsibility of people with mental health problems.
- 12 Carers' support groups are run both in the community, facilitated by carer support workers, and by health care professionals within specific services such as: learning disabilities, older peoples' services, dementia services, eating disorders, chronic fatigues. These groups exist purely to support people in their specific caring roles, and facilitate peer support between carers.

Glossary

ASC	Adult Social Care
BME	Black and Minority Ethnic
CAF	Common Assessment Framework
CPA	Care Programme Approach
DASS	Director of Adult Social Services
DCS	Director of Children's Services
DLA	Disability Living Allowance
EDT	Emergency Duty Teams
LCC	Leeds City Council
LPFT	Leeds Partnerships Foundation Trust
LTHT	Leeds Teaching Hospitals Trust
SEN	Special Educational Needs
SENCO	Special Educational Needs Co-ordinators
SILCS	Specialist Inclusive Learning Centres



Drama group for carers held at Touchstone Support Centre (a MEMHO project)

APPENDIX Leeds Carers Charter

Leeds Carers Charter

A carer is a person who provides care for someone else who, because of long term illness, mental illness, impairment or old age, is not able to care for him or herself.

A carer can be:

- A parent
- A son or daughter
- A brother or sister
- A husband, wife or partner
- A relative, friend or neighbour

A carer is someone who is not paid for the care they provide.

Young carers are children and young people who take or share responsibility for the care of another person (Carers Act 1995).

If you are a carer, using our services, you can expect:

- To be recognised, identified and valued for your caring role and be treated with dignity and respect.
- To access, or be signposted to, relevant and up to date information about the support that is available for you as a carer.
- Our staff to inform you about the right to a carer's assessment and to be referred appropriately - if you wish.
- Your own health needs to be recognised and to be supported to maintain your physical, mental and emotional health and well-being.
- To be included (with the permission of the person you care for) as a valued partner in the planning and delivery of his/her treatment and care, and in particular in discharge planning.
- To have the right to choose the level of care you are able to offer, depending on your age and ability.
- To be considered as an individual, and for services to strive to reflect your own needs.
- Have opportunities to comment on, and be involved in, the wider planning and evaluation of services.

If you need more information on this charter please contact:

NHS Leeds:
0800 0525270 (PALS)

**Leeds Teaching Hospital
NHS Trust:**

0113 206 7168 (PALS)

**Leeds Partnerships NHS
Foundation Trust (LPFT):**
Contact LPFT Carers Support
team on 0113 295 4445

Leeds City Council (LCC):
Services for adults
0113 222 4401
Services for children and
young people 0113 222 4403



Working in conjunction with NHS Leeds, The Leeds Teaching Hospitals NHS Trust and Leeds Partnerships NHS Foundation Trust

Signatories to this Strategy

- Leeds City Council
- Leeds Teaching Hospitals Trust
- NHS Leeds
- Leeds Partnership Foundation Trust
- Age Concern
- Carers Leeds
- Alzheimer's Society
- Carers UK Leeds Branch
- Willow Young Carers – Barnardos

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