



Putting Older People at the Heart of our Work in Leeds



Leeds at heart.

Approximately 1/5 of the UK population is of state pension age (which is between 61 and 68 or older, depending on age and gender). Life expectancy has been growing steadily for over half a century. Longer life expectancies mean that people will be living longer, sometimes with poor health, physical and mental disabilities or dementia. This means that more people are likely to require care and support.

1. LEEDS COMMUNITY FOUNDATION

Leeds Community Foundation fulfills a vital role in the City, connecting people who have achieved success and want to give something back, with some amazing community projects who need financial support and practical help. We are the largest independent grant-maker in Leeds and since 2005 we have given out over £20 million in grants to nearly 1,500 Community Groups and charities. We specialise in creating grants programmes that have a lasting effect primarily in disadvantaged communities. We work closely with individuals, companies and organisations in order to align their areas of interest with the needs of local communities. Many people ask us what are the “needs in Leeds”. In response to that we have produced a number of publications that can be found on our website (www.leedscf.org.uk). One of them (Needs in Leeds) provides an overview across the City. This paper - putting older people at the heart of our work in Leeds - focuses specifically on the needs of older people in the City.

2. EMERGING NEEDS OF OLDER PEOPLE

Approximately 1/5 of the UK population is of state pension age (which is between 61 and 68 or older, depending on age and gender). Life expectancy has been growing steadily for over half a century. In 1951 a man could expect to live until 77, today it is likely to be 86 and by 2050 to be 91. This has meant that the number of older people has also been rising steadily. The 2011 census revealed that there are now more people in the UK aged 60 and above than there are under the age of 18.

And the numbers are likely to keep on rising. The Office for National Statistics (ONS) latest figures predict a 46% rise in people over the age of 65 between 2010 and 2030 in Yorkshire. The number of people over the age of 85 will almost double in the same period (increase of 90.3%).

There are more people in the UK aged 60 and above than there are under the age of 18.



Longer life expectancies mean that people will be living longer, sometimes with poor health, physical and mental disabilities or dementia. This means that more people are likely to require care and support so they, and their carers, can continue to live independently as long as possible. Older people are, understandably, a high priority in terms of national and local policy. The two main issues are:

- Firstly, the need to recognise older people's contribution as active citizens and valuable “community assets”. Our ideas about aging are changing. People are living longer and continuing to contribute to their communities in all areas of life - working longer, helping with child care, volunteering and providing strong community leadership. Volunteering is a way of keeping a life for older people - it's good for their well-being as well as an important contribution to community life. A national study suggested that older people currently provide informal volunteer services to their community of over £10 billion - each year - and that figure is predicted to grow as our older population increases. Approximately 39% of 65-74 year olds volunteer.

- Secondly, to support health and well-being it is essential to create a climate which promotes good health and maintains independence, including making preventative services and resources available. Promoting health, preventing ill health and maintaining independence and quality of life are what older people want. One of the most critical emerging needs is how to tackle social isolation as this has huge implications for poor health as detailed below. An interesting observation from T. Scharf writing on urban loneliness was “there is an increasing tendency to design cities around needs of younger people; high population turnover making it difficult to keep longstanding connections; social issues such as crime and anti-social behavior which conspire to alienate older people.’



Those most at risk include: the “oldest old”, those on low incomes, living alone, in isolated rural or deprived urban areas and those suffering from poor physical or mental health.

3. THE STATISTICS FOR LEEDS

Local statistics mirror the national trends.

The ONS mid-year statistics for 2010 show Leeds has a population of 798,800 people. 97,400 are between 60-75 and 55,200 are over 75. At the same time the number of people over the age of 85 has risen by 15% in the last 10 years and is set to rise significantly between now and 2020. This means that there are over 152,000 people over the age of 60 in Leeds i.e. almost 20% of the total population. Of these, approximately 42,000 people live alone. Between 2010 and 2030 the number of people over 65 living alone is predicted to rise by over 37% and those over 75 by 40%.

Old age is not in itself a form of disadvantage but, when accompanied by poverty, ill health and isolation, it gives rise to a distinct set of needs which need to be addressed. The key issues affecting older people in Leeds are primarily linked to poverty and health. Whilst funding cuts that impact our communities and local services affect everyone, older people tend to rely more on local solutions to their needs, and are less able – physically or financially – to access alternatives.



- Leeds is ranked 104 out of 377 local authorities in the country for the number of people on pension credit (only accessed when weekly income for a single person is below £145.40 a week or £222.05 for couples)
- The index of deprivation figures for 2010 show that 150,000+ people in Leeds live in areas which are in the 10% most deprived nationally. A study by the University of Leeds in 2006 revealed that the wards that contain a significantly higher proportion of older people are almost entirely in the outer areas of Leeds, but there are smaller populations of more vulnerable older people remaining in the inner city wards.
- There are well recognised effects of deprivation on health and well-being. The highest increase in diagnosed dementia is within areas of deprivation – but it is recognised that probably only half of the people with dementia ever get a diagnosis.
- Leeds has a vibrant and diverse population with approximately 140 ethnic groups representing 17.4% of the total population (127,000 people). A study by the University of Leeds in 2006 revealed that: there were relatively few older people from ethnic minority communities but, as 70% of the ethnic minority population lived in only nine wards, the majority being in the most deprived 10% Super Output Areas.

4. LOCAL CONTEXT

4.1 Statutory Responsibility

Leeds City Council's Adult Social Care directorate supports older people, as well as people with mental health problems, sensory impairment, physical impairment and learning disabilities, with a responsibility to protect people from abuse and neglect. The directorate: provides direct services through staff (including Assessment and Care Management) works with NHS Leeds and other statutory providers and invests approximately £176m p.a. through contracts with third sector and independent partners to deliver services for eligible service users and a significant investment in early intervention and prevention.

The directorate, with strong support from Councillors, adopts an open and progressive approach to the provision of services. They are keen to encourage enterprising activity, are open to new ideas and, where possible, adopt a collaborative and co-production approach to dealing with the issues and to service development.

Further information about the Council's policies and priorities can be found in the State of the City Report (www.leeds.gov.uk/council/Pages/State-of-the-city-report.aspx) and the Joint Health and Wellbeing Strategy (http://www.leeds.gov.uk/docs/JHWS_FINAL_web.pdf).

Responsibility for the provision of healthcare falls under the remit of the NHS, who liaise closely with ASC to attempt to provide joined up pathways of care that manage situations whereby older people move into and out of hospital and other care settings.

The integration of Health and Social Care is a major priority in the city (Leeds is a 'Pioneer on integration') and it is notable that much of this work is focused on 'frail elderly' and those with long term conditions.

Healthwatch Leeds (HWL) has recently been established to give local people a more powerful voice about health and social care services and help them to influence the design and delivery of local services (www.healthwatchleeds.co.uk).



An Ageing Well Board has been set up as a multi-agency partnership to develop a more strategic approach and a Charter for Ageing Well. This includes key organisations such as the NHS and Leeds City Council, as well as the Universities and METRO. Two of the major initiatives the Ageing Well Board is supporting are:

- Becoming a dementia-friendly city (see below)
- Being part of the Global Network of Age Friendly cities

The directorate also supports a wide range of third sector related activity including:

- The Leeds Directory, an online and paper-based directory with information about goods, services and events that older people and other potential users might want, or could benefit from.
- Better Lives through Enterprise which aims to stimulate the social care market in Leeds through:
 - o Better Lives Leeds: a grants and support programme to stimulate the development of social enterprises to develop business ideas for services that could encourage market development of activities and services that support older people to remain independent.
 - o Local Links: a community-based initiative working with some of the NNS to develop community brokerage
 - o CR: working with the private sector to show how working with older people's groups can be a key part of a Corporate Responsibility strategy.
 - o Volunteering: matching people to opportunities in the health and social care sector and promoting ideas of reciprocity.
- Financial and practical support for the 37 Neighbourhood Network Schemes
- Support for the Senior Network Support project (SeNS) which uses "community connectors", local people who network with others in an area to find out what assets already exist in the community.
- New initiatives such as "time-banking" where 1 hour of time is treated as 1 credit and you then swap skills. It's very simple in concept but can be really positive, and help rebuild a sense of community spirit and trust by providing people with mutual support.



4.2 Third Sector

The over-arching forum is the Leeds Older People's Forum www.opforum.org.uk. They have a membership of over 100 voluntary sector organisations who are working with older people across Leeds, including the Neighbourhood Network Schemes (NNS). The Forum supports its members and ensures the voluntary sector is involved in planning, developing and managing services for older people in Leeds. The Forum also have a significant role as 'the voice of older people' in the city. They are a good link between the sector and the Council, publish some interesting research papers and a monthly bulletin to members.

There are over 150 organisations in Leeds with a specific focus on older people.

We estimate that there are over 150 organisations in Leeds with a specific focus on older people. They provide a range of help and support as detailed below.

- Advice, information and support: advice clinics, drop in sessions, information days; help with claiming benefits; advocacy; bereavement support; befriending; dementia cafes; support for carers.
- Healthy living: advice and awareness; aerobics/gentle exercise, dancing pilates/Tai Chi, swimming, walking, health fairs, healthy eating and cooking.
- Leisure and recreation: arts and crafts, singing, theatre groups, gardening clubs, inter generational activities; IT classes; outings and trips.

A total of 37 groups are part of a citywide Neighbourhood Network Scheme. (www.opforum.org/nns)



These are community-based, locally led organisations that help older people live independently and play a more active role in their local communities. Each scheme covers a specific area and is part-funded by Leeds City Council. The Neighbourhood Network Scheme try to address everything older people might want or need in order to lead happy, healthy and independent lives. They do this by: organising classes, trips and holidays, running social and exercise groups, giving information and advice on things like benefits, form-filling and winter warmth, and offering practical help such as handymen, home security, transport and hospital escorts. Many offer additional services including: intensive support at home, winter warmth information and hospital discharge support.



The number of older people registered with the Neighbourhood Networks has increased by 7.4% in the last year to 21,500 as of 31 March 2012. There has also been an increase of over 9% in the number of older people from black and minority ethnic communities accessing these services in the last year.

Leeds is also home to national charities such as Age UK Leeds. They help around 3,000 people aged over 50 each year in Leeds with advice and information whether that be on money matters, consumer issues, or helping someone find a trustworthy tradesman. There are also a number of independent groups, not part of the NNS, that target support at older people specifically, or where older people are part of the community they provide help to. These include generic services such as British Red Cross and the Royal Voluntary Service and those focused on particular communities of older people, for example Leeds Irish Health and Homes and Hamara.



Many of these community organisations are found in the most disadvantaged parts of Leeds, tackling some of the city's biggest problems. Many of them are quite small, with few resources. Some have no paid staff and are totally reliant on the goodwill of volunteers. The kind of support they provide is much needed and well-appreciated.

5. WHAT ARE THE KEY NEEDS IN LEEDS?

Below you will find a brief explanation of some of the key issues facing older people in Leeds. In order to illustrate what is being done to tackle these by third sector organisations in Leeds, we have given some specific examples of projects funded by Leeds Community Foundation (LCF).

Some have no paid staff and are totally reliant on the goodwill of volunteers.



5.1 Loneliness, social isolation and exclusion

A report by the Campaign to End Loneliness in June 2013 concluded “isolation and loneliness is as bad for our health as smoking 15 cigarettes a day, and worse than obesity.” They estimated that 20% of the older population are lonely sometimes and 10% are intensely lonely. Looking at Leeds this means that of the 150,000 aged 60+ in Leeds, over 15,000 of them could be intensely lonely.



Acknowledging loneliness can be difficult for anyone. Often people deny or minimise their need because there is a stigma to feeling lonely or ‘needing’ help. Many older people find themselves on a spectrum that starts with loneliness and progressively gets worse until it is referred to as social exclusion. Loneliness is more often used to refer to isolation or lack of companionship or connectedness and can occur even when someone is surrounded by other people. Social isolation is a complete or near-complete lack of contact with society and is usually involuntary. Full-blown social exclusion is when someone is prevented from fully engaging in society and can be the end of a gradual process of disengagement from society.

The causes of loneliness and social isolation are varied.

- Older people are particularly vulnerable through loss of friends, family, mobility or income.
- Events in later life can be a trigger such as bereavement, moving home, children moving away, falls and other health incidents.
- Other causal factors are: low income, poor housing, poor physical health, the fear of crime, family breakdown, lack of transport, living in city centre high rise flats or rural living and living alone.
- Particular groups of older people will have additional factors that impact on loneliness including Lesbian, Gay, Bisexual, Transgendered, history of mental health, ethnicity, etc.
- Most significantly the lack of a phone is a key factor.
- Sadly “ageism” can also contribute towards social isolation and exclusion in later life i.e. attitudes towards older people held by individuals, the media and those who design and deliver services. This can lead to older people being more marginalised, receiving sub-standard care in hospitals and health settings or more being given less assistance with pain management.



Taking lack of transport as an example: 33,000 older people in Leeds don't have a car and this dramatically limits their mobility. Whilst they can use alternative transport for "serious" requirements, it is the discretionary trips that contribute significantly to the quality of life that may be lost. This serves to increase isolation and is compounded by concerns about safety, an inability to walk longer distances to public transportation, and a lack of simple things in public areas, including level pavements, benches to sit and rest on, and public toilets. This, coupled with low income, means that many older people cannot afford access to social and other activities.



The impact of social isolation on physical and mental health is significant and this has major cost implications for health and social care services.

- A study of over 6,500 men and women aged over 52 in the UK found that social isolation was linked to higher mortality rates - a 26% higher risk of death in older people over a 7-year period.
- The Campaign to End Loneliness report stated that socially isolated and lonely adults are more likely to undergo early admission into residential or nursing care and they highlighted the fact that older people who are lonely are at higher risk of the onset of disability.
- Studies show that being lonely has a significant and lasting negative effect on blood pressure and increased rates of cardiovascular disease.
- Loneliness is also associated with depression (either as a cause or as a consequence), poor general mental health, cognitive decline and dementia.



It is in this area that the voluntary sector has a particularly significant role to play, helping alleviate isolation and improve the quality of life of older people through one-to-one interventions, group services and wider community engagement. A report by the Social Care Institute for Excellence called "Preventing Loneliness and Social isolation among older people" in May 2012 concluded: "tackling loneliness and social isolation among our ageing population is a challenge we cannot ignore, both at an individual and wider community level. The voluntary sector is currently delivering the majority of the interventions. There is vital need for health and social care statutory services to work alongside the third sector to tackle the problem successfully"

Examples of intervention are given below. It is particularly welcome by people who are frail and who find it difficult to leave the house and has a modest but significant effect on depressive symptoms. The savings are found to outweigh the costs of delivering befriending.

- Befriending - offering lonely and isolated older people vital companionship and emotional support. This is often reliant on volunteers visiting individuals in the home, or providing advice over the phone.
- Support services such as transport or picking up medications, or shopping.
- Group Services - day opportunities, lunch clubs, social schemes. This includes friendship, creative and social activities, health promotion and exercise. Research evidence is particularly supportive of social group activities with a creative, therapeutic or discussion-based focus.

Burmantofts Senior Action (BSA)

BSA supports older people to live independently in their own homes in the Burmantofts area of East Leeds. They offer services such as decorating, gardening, winter warmth, advice and information and activities including luncheon clubs, dementia café, stroke club, friendship/drop in group, craft group, day trips, parties, fundraising events, exercise classes and a book club.

Via Leeds Community Foundation, the Henry Smith grant funded the salary of a Neighbourhood Worker who helped with the above services and activities, and was also responsible for visiting people in their homes and assessing their needs. A good example of her work is how she helped a local 68 year old lady who lived alone, estranged from her husband who suddenly died. As she was still married, the responsibility of the funeral was left to her but she had very little money and became increasingly depressed about the funeral expenses. The Neighbourhood Worker helped by getting financial help from SSAFA, as well as securing some furniture from a local charity. Then, in a short space of time, she was robbed by a sneak thief and then her dog and best friend both died. She was absolutely devastated but with the help and support of the Neighbourhood Worker, she is now getting out and about and is attending activities at BSA once again. It is a slow road to recovery but BSA will work with her until she is able to tackle things alone.

In a single year the Neighbourhood Worker made 187 home visits, offered information and advice to 53 people. 10 were introduced to a befriender and 59 people were given emotional or general ongoing support. She made referrals to organisations such as Fire Service, benefits advice, G.P's, care & repair, police and housing on behalf of older people who don't feel confident enough to do it themselves. Over the festive season, she delivered food parcels to some older people in the area.



Holbeck Elderly Aid used a small grant of £2,500 to run a pilot scheme called 'Be a Good Neighbour'. This alerts people in the community to watch out for elderly neighbours in winter. This could be a friendly phone call to see if they are alright, calling round to see if they need anything, getting volunteers to do the shopping. Workshops with different groups of older people were held at various locations in Holbeck to give out information and advice on 'Wrap up Warm' and temperature thermometers.

The story of Nora, a lady of 84, says it all. She was living alone, quite disabled after a stroke and hip fracture and a bit forgetful. She received intermediate support after the two hospital incidents and was given a list of numbers for help. However, having failed to get home care because she was not eligible, she did not make any further contacts. She lived, lonely and miserable, quarrelling with her family because she wanted them to visit her more often. Eventually her neighbour telephoned the local Neighbourhood Network scheme and asked if she could attend the lunch club. Since then, Nora feels her life is transformed. She has been helped to obtain Attendance Allowance, has bought a new wheeler to walk out to local shops, can use a taxi to attend the doctor, is paying a cleaner to help in the house and has been on holiday with the scheme for the first time in 32 years. The NN have arranged for the path outside her house to be repaired as it was unsafe, they take her on the assisted shopping bus once a fortnight and she goes regularly to social groups, even, to her own amazement, attending the computer class. Before she received this support she said "I felt like sticking my head in a gas oven."

5.2 Poverty and older people

Although average pensioners' income has grown faster than average earnings, pensioners remain a low income group. Women are especially disadvantaged, with an average gross weekly income of £264 compared to £304 for men. Research conducted by the Joseph Rowntree Foundation in 2012 revealed that the poverty rate for pensioners has actually fallen in the last 20 years but remains quite high, at 17%.

Many older people live on fixed incomes, with little opportunity to earn more. They are facing reduced returns from their savings as well as an increase in the costs of services and support. Fixed incomes render people vulnerable to price rises brought about by government interventions to counteract the impact of recession. Rising cost of essentials, such as fuel and consumer goods, can have a detrimental effect on the health of older people if they become unable to maintain a comfortable indoor temperature or follow a healthy nutritious diet.



St Vincent's Support Centre is based on the York Road. They have a team of people who provide help and support for local people in East Leeds, including older people. They can provide emergency support to people struggling to pay heating and food bills, as well as providing emergency food parcels to families. This, however, is more of a quick fix and their core aim is to work with a family over a longer period of time to address the root cause of financial difficulty. Our grant of £2,500 enabled them to work intensively with a number of older people to address some of their issues.

'Fuel Poverty' - Is the term for when someone has to spend more than 10% of their household income on heating costs.

5.3 Fuel Poverty

Households are considered to be in "fuel poverty" if they have to spend more than 10% of household income on heating costs to keep their homes in a satisfactory condition. Fuel poverty depends on three main conditions: the cost of energy; the efficiency of the home; and the household income. Local residents have no control over the first element, although costs have been rising steadily over the past few years. Older people tend to live in older properties which, by their very nature, are less fuel efficient and they often have a fixed household income, with less ability to generate more money through earned income.

A report by AGE UK in 2013 revealed that many households face a gap of £438 between the cost of their bills, and what they can afford to pay. They estimated that £2.4m households across the UK are unable to pay to keep warm and, of those, 30% had inhabitants over the age of 60 - a total of 720,000.

The statistics for Leeds show that

- 19.6% of households in Leeds are deemed to be in fuel poverty
- In 19 local areas in Leeds, 25% or more of the households are in fuel poverty with some areas showing figures as high as 34.7%
- The number of single pensioner households in fuel poverty is estimated at 4 in 10

Faced with rising costs and fixed or reducing income, many older people have to choose between "eat or heat" in the winter months as they cannot afford to both eat hot meals and heat their homes. Here are examples of just two projects LCF has funded:

Action for Gipton Elderly: £2,500 Winter Warm Packs delivered to 315 vulnerable elderly in Leeds 8 and 9. The pack contained warm blankets, bedding, thermal underwear, bed socks, gloves, hats scarves, ice grips. It also included emergency food supplies such as long life milk, bread, soups, tinned meats, tea, jam, porridge and fresh produce etc. Packs contained easy-to-read winter warmth information, giving tips on energy efficiency, keep warm keep well.

Zest Health for Life: £2,500. This enabled them to run 12 winter warmth awareness days at the All Being Well stall in Leeds Kirkgate market. They were able to take a minibus to bring in older vulnerable people from North East Leeds into the market to purchase cheap, nutritious vegetables. They could then take them to the stall and learn how to create healthy hot soup.



5.4 Debt and older people

Research by ILC-UK for Age UK revealed some interesting findings, summarised below.

- Increasing age is associated with more negative views towards debt and older people have often been thought to be better able to live within their means. However, low returns on savings, decreasing annuity rates and rising prices of energy and general living costs are adding to the financial pressures on many older people.
- The amount owed by those in debt has increased substantially between 2002 and 2012.
- Problem debt amongst older people with unsecured debts rose from 23 to 28% between 2002 and 2010 with more younger older people being affected. This may be because younger older people are more used to credit cards and borrowing than older pensioners.
- More people are reaching retirement with a mortgage and the Financial Conduct Authority (FCA)'s report revealed that 40,000 householders aged 65+ have an interest-only mortgage that matures between 2017 and 2032. Half of these will have a shortfall of more than £50,000 as the endowment policies they may have taken out have not increased sufficiently. If they don't have sufficient income to pay back the shortfall, they may risk losing their homes.

The causes of debt are many and varied. They include: major life changes such as bereavement; being forced to stop work through illness or redundancy; inheriting hidden debt of a spouse following their death; getting into trouble with high interest store cards or unscrupulous lenders.

The impact is significant. For older people trying to manage ongoing debt, or facing problems for the first time, this can have a devastating impact on their lives. In many instances it leads to stress, depression, health problems, marital breakdown and a decreased quality of life in general.

For older people, trying to manage debt can have a devastating impact on their lives.

Although there are no hard and fast statistics about debt problems for older people in Leeds, advice agencies and some of the neighbourhood networks are seeing an increase in enquiries about debt, bill payments, rent or mortgage arrears and payday loans.



Leeds Older People's Forum used to have a Debt Advice Manager. She tells the story of an 87-year old woman, whose washer had broken so she took out a £200 payday loan, didn't understand the terms, couldn't pay back within 28 days and then agreed to pay interest at £53 a month until she could clear the loan. She ended up owing £2,200 on a £200 loan. Luckily the manager was able to intervene. In a single year the Debt Manager paid 490 home visits and was able to secure £722,000 in extra benefits and arrange for £577,000 bankruptcies / credit card debts to be written off.

Ebor Gardens Advice Centre is based in LS9, in East Leeds. They provide a vital debt advice and casework service that helps people understand their debt and come to a realistic agreement with creditors. They also accompany people to County Court in relation to repossession and eviction hearings. In a three-week period in December alone, their two part-time advisors deal with over £250,000 worth of debt. An LCF grant from Jimbo's fund enabled them to pilot a home visiting scheme to the over 60's, working alongside Burmantofts Senior Action. The results of this were encouraging and showed a clear demand for this kind of help.



5.5 Mental and Physical Health

Good mental and physical health is fundamental to the way we all live our lives. As people are living longer, they are more likely to have health problems. Some of the most significant statistics in Leeds, are:

- There are over 56,779 people aged over 65 in Leeds with a limiting, long-term illness. Nearly 24,000 of those live alone. (YEP, 2011).
- Cordis Bright used information from The Projecting Older people's Population Information (POPPI) during 2009 to estimate the social care needs of the over 65 population in Leeds. They found that approximately 35% of older people had a social care need i.e. 39,500 people over 65 in Leeds with some level of need. Of these they proposed that 3,300 of these were potentially in need of high levels of statutory social care with the remainder being supported through less intense packages of care and beyond that by informal support networks and carers. (POPPI).
- In 2011, 42% of hospital admissions in December and January were people over 65. (YEP, 2011)
- Older people have the highest suicide rate for women and the second highest for men of any age group. (YEP, 2011).
- It is generally acknowledged that at least 30% of unplanned admissions of older people to hospital are not necessary and those admissions often lead to poor outcomes, including admission to long-term care. "Services need to be re-aligned, therefore, to face the front door of the hospital rather than the back door." (ASC Market Position Statement 2012).
- In September 2010, there were an estimated 38,491 people over 65 who are unable to undertake at least one self-care activity and 47,000 unable to complete at least one domestic task. This is potentially likely to increase by 2,500 over the next five years and by 17,000 over the next 20 years. (POPPI).

One of the most significant issues facing the City in terms of health is the increase in the number of people with dementia. The 2012 POPPI projections for Leeds are that there are at least 8,607 people in Leeds with diagnosed dementia, over 10,000 people over 65 have depression, and 3,232 have severe depression. Of those living with some form of dementia, it is estimated that 5,600 live at home. Taking national statistics that one third of people living with dementia in the community live alone it can be estimated that 3,696 people live with their family. It is these family members who will be providing care and support to a greater or lesser extent. In addition, other carers will be looking after their relative with dementia from a distance - mostly sons and daughters. These figures are estimated to increase by 35-40% by 2028 (Leeds Dementia Strategy 2011).

One of the greatest barriers facing people with dementia is the negative attitudes others often have towards their condition. Fear and misunderstanding can lead people to treat those with dementia insensitively. Recent examples in Leeds include a person being banned from a supermarket after forgetting to pay and a bus driver refusing to let someone on the bus, thinking they were drunk. Leeds is taking a citywide approach to addressing the stigmas attached to dementia and promoting the idea that dementia is everyone's business.

10,000 people over 65 have depression.

In March 2012 Leeds signed up to become a 'dementia-friendly' community, one of six across the country (www.leeds.gov.uk/dementia). The aim is to create a city and communities where people with dementia and their relatives and carers: would not feel stigmatized; would feel confident about seeking help, and would be supported to continue with day-to-day activities. They would be able to go into shops, use public transport and access other local services knowing that they would be treated with tolerance and understanding. Businesses and other local services would respect the needs of people with dementia and take these into account when planning their environments and training their staff.



Care and Repair Leeds received a £20,000 grant from Jimbo's Fund to set up a new project to create a lending library of approximately 100 activities and therapeutic resources to enable those with dementia to access a wide range of reminiscence, music and sensory stimulation products. Based on a traditional lending library model products were lent to family, friends and carers for a set duration. The pilot was launched in East Leeds with activities being listed in a catalogue widely circulated and bookable over the phone. The grant helped to fund a part-time outreach worker who delivered the items and used this to ascertain what other help they might need, or identify an opportunity for a potential referral to other support organisations.

They were able to support 240 adults, including 160 people over 65. Here is what Mrs Webb said about the service, used by her husband, Peter, who has Alzheimer's: "when someone has Alzheimer's, conversation can become very difficult and this library is a way of keeping that connection alive."



It's not just the older people who are helped, but their family too. Below is an extract from a letter received by one of the NN schemes from the daughter of someone they had supported.

"I wanted to tell you about the huge difference that you have made to my dad's life over the last 5 years. My father was 85 years old when in 2008 my mother, his beloved wife of almost 60 years, died very suddenly of a stroke. That she might die before him had, quite simply, never crossed his mind and he was emotionally devastated. Overnight, he lost all structure to his day, his week and his year. The familiar rhythm of the day - with three meals cooked by my mother; of the week - with visits to Leeds, to the shops and to take my mother to the hairdressers and the College of Music; and of the year - with the annual 6 week caravanning holiday were gone, quite literally at a stroke.

He was lost - emotionally and physically. He had to learn new skills such as planning meals, shopping and cooking, and using a washing machine for the first time. Within a month of her death he suffered his own significant health problems (a heart attack, coronary artery bypass graft and a small stroke) and this coupled with his failing eyesight meant that he had to give up driving and sell his car, thus losing his independence.

I am an only child and work in a busy and demanding job as a GP, 30 miles away. This time was also very difficult for me because I was the only person providing practical and emotional support and this was a great strain with the other demands on my life, including those of my husband and three children. When we heard of your group my father was reluctant at first, he did not really want to socialise and particularly not with people who, unlike him, were 'old'. He started to go to the coffee mornings and to the talks. Some of these he enjoyed, others gave him something to grumble about. It was excellent that he was starting to get a bit of spirit back. He also went on many of the excursions, the Christmas meals and received a hamper at Christmas. It was not that he needed the food, or was hungry, it was the kindness of the gift and the thoughtfulness of those who had put the hamper together that made him cry.

My father was always somewhat physically lazy and I had to persuade him to go to the exercise class which, to his surprise, he began to enjoy and was amazed to find that he felt physically fitter each week. As my father approached 90, there were times when we wondered if we should arrange for him to move house nearer to us, but we all realised that moving out of the area would diminish my father's life in a way that we, the family could not put back. The involvement of your organisation in my father's life was transformational. It gave him structure to his week. It gave him practical help and independence enabling him to do his own shopping. It helped keep him safe at home, when there were minor problems in the house, you provided a list of trustworthy household repairers who were able to fix problems quickly and without the worry of him being overcharged or worse. Wonderful as this practical help was, OPAL actually did something much more subtle and complex. By providing real, authentic and genuine care - a real rarity in my own experience as a GP - you gave my father back his sense of self-worth; of being a valued person who was cared for not just by his family but by the wider community.



5.6 Carers

Carers are people who provide unpaid care by looking after an ill, frail or disabled family member, friend or partner. National census figures for 2011 showed an 11% increase of 629,000 over the previous 10-year period from 5.22 million to 6m. An estimated 6,000 people take on a new caring role every day.

Leeds has a total of 71,600 carers. Over 45,000 provide up to 19 hours a week, almost 10,000 provide 20-49 hours and over 16,000 provide 50 hours or more a week of support. The recent census doesn't show a significant rise in the total number of carers in Leeds, but does show an increase in the amount of care being provided, particular those carers who provide more than 20 hours a week.



When examining the rise in older people who are carers, the 10-year rise is a staggering 35% so that there are now 1.3m older people who are devoting their retirement to caring for ill partners or their own ageing parents. This means that more people over 65 are now spending time caring for "older-old" people in their 80's and 90's. This is a challenge that previous generations have not faced. In fact, the number of older carers has risen more rapidly than the total number of carers.



Caring has huge emotional, physical and financial effects with carers often struggling to balance work with their caring responsibilities and 45% of those surveyed at a national level said they had to give up work. The 2001 census found that 3m people combine work with caring responsibilities for a disabled, ill or frail relative or friend. This is approximately 1 in 8 workers in the UK with 2m working full-time and 1m part-time. An astonishing 400,000 people combine full-time work with caring for someone for 20 hours a week or more. In Leeds, of the working age carers a total of 67% still work. 69% of male carers remain in work and, of those providing care for more than 50 hours a week, 40% are also working full-time.

A survey for Carers Week 2012 revealed that the majority of carers (82%) said caring had a negative effect on their physical health, including injuries as a result of manual handling; 87% said caring has had a negative impact on their mental health, including stress and depression. This is made worse by the carers finding it harder to make time to attend their own medical check-ups or treatment, with 2 in 5 carers saying they had to put off treatment because of their caring responsibilities because they could not trust or afford to pay for replacement care. Research by Carers UK includes cases of carers discharging themselves from hospital because of a lack of alternative care.

Caring can also put strains on existing relationships and can result in the social exclusion of carers themselves. 52% having experienced difficulties with their partner and 61% having less time to maintain relationships with friends.

Caring often means that a family's income decreases as their ability to work diminishes. This is often compounded by additional household and living expenses associated with ill-health and disability - extra heating, laundry and transport costs. Families find that disability benefits do not cover all these costs so many end up having to pay for care themselves - spending their own income or using up their savings to pay for the care of the person affected. Almost half of those surveyed by Carers UK reported they were cutting back on essentials like heating and food in order to make ends meet. This, in turn, can lead to debt and money worries as detailed above. 74% struggled to pay bills, 52% were cutting back on food to make ends meet and 32% were falling behind in mortgage and rental payments.



In Leeds, just 5,280 carers (out of a total of 61,000) receive Carers Allowance. This is paid by the Department of Work and Pensions to carers providing 35 hours of care per week to a person who receives Attendance Allowance or the higher two rates of Disability Living Allowance, or Promoting Independence Payment. Carers receiving Retirement Pension or sickness benefits are excluded, as are carers who are in employment and earning above a specified amount of earnings per week.

Older carers are also spending more time helping look after grandchildren, often at the same time as they are caring for older parents.

Carers Leeds are the number one organisation for advice, information and support for carers in Leeds. One of the services they offer are 12 support groups they run where people can share information, get confirmation that their feelings are "normal," educate others, make friends, or just let off steam. Some are generic and based in a geographic area, others are specifically for carers caring people with specific illness or disability e.g. Asperger's, Parent Carers groups and Dementia. The groups operate in the heart of local communities which is key because many carers feel they cannot leave the home for a long period of time and getting into the city centre is costly. An LCF grant of just £5,244 enabled them to run 11 monthly sessions for five separate groups across the City.



“Miss R, aged 64, lives with her grown up son (aged 28) and acts as his carer. Her son experiences paranoia and daily chronic headaches and cannot leave the house unless she accompanies him. Over a period of 2 years we have helped Miss R’s son to claim ESA for the first time (previously he wasn’t claiming any benefits and relied on his mother for money), and successfully made 2 appeals which have eventually resulted in him being placed in the ‘support group’. Miss R cannot read and write so we regularly help her to complete forms and other correspondence. We have also helped her to access emergency food aid and assistance with heating bills when her son’s ESA was cancelled and she went overdrawn at the bank as a result.”

5.7 Emerging Trends

Research undertaken by the Leeds Older People’s Forum (LOPF) in 2012 identified the following issues that affect older people in particular:

- Access to comfortable and secure homes
- An adequate income
- Safe neighbourhoods
- Ability to get out and about
- Friendships
- Access to learning and leisure
- Able to keep active and healthy
- Access to good relevant information
- Involvement in planning and decision making
- Freedom from age discrimination

In 2013, together with LOPF, LCF did a survey of local groups to find out what the emerging trends were. Although we have no hard and fast statistics, the reports from the frontline groups revealed some key common factors.



Younger, older people: this primarily refers to people in their late 50’s to early 60’s. Several of the groups referred to an increase in the number of referrals from this group. The issues include:

- They are often more active, want to do their own thing and don’t want the “traditional” model of group activities. One report was called “don’t call me old dear” showing how some older people don’t want to be associated with an older people’s charity because they don’t want see themselves as old. The good news is that many of them are joining the schemes as volunteers!
- Many of these so called “baby boomers” have multiple issues including chaotic lives, addictions and challenging behaviour. This means they are very demanding and resource heavy. Many only turn to the local schemes when they reach crisis point and don’t know where else to go and they are the same people who often have the most complex needs.

Addictions: A new but growing trend (sometimes associated with the younger, older people identified above) is the rise in older people with issues around alcohol and drug addiction. This is not only a tricky issue to handle on its own, but it is often associated with anti-social behaviour which can also be disruptive. It can also lead to more health concerns such as falling in the house.

A new but growing trend is the rise in older people with issues around alcohol and drug addiction.

Debt and Social Isolation: a number of respondents cited an increase in social isolation and increased concerns about the cost of living.

Dementia: the most common response from groups was the huge increase in the number of people with dementia.

Specific needs of BME elders: one respondent was working directly with BME elders and had commissioned a research report. Given the rise in numbers of people from a minority ethnic background, we can only assume that the issues described below will become more prevalent:

- A need to identify cultural, religious and individual beliefs that care is more often provided by the family, not by the state. South Asian families, in particular, are becoming more diverse and the dependence of older family members on younger family members will decrease, over time.
- A cultural reluctance to accept care from the wider wider community or state, as it implied a failure of their families to accept their responsibilities.
- Higher levels of isolation among female BME carers.



6. OTHER SIGNIFICANT ISSUES

There are also some broader changes taking place that have a direct impact on the lives of local older people, and on the community projects that provide them with support.

6.1 Reduction in Funding

Leeds Adult Social Care had a budget of £176.5m in 2011, down almost 2% from the year before. Following the national Comprehensive Spending Review in 2011 (CSR), Leeds City Council has to make savings of £150m+ over 3 years.

Whilst they are doing what they can to protect frontline services, they are also having to take significant decisions about funding priorities. Since 2011, a total of 13 buildings have closed including at least four residential homes for the elderly and four day centres. In addition, there has been a cut of up to 15% in terms of grants from LCC to voluntary organisations.



For many, this cut from the Council is further augmented by cuts from national government departments, or reduced funding from charitable trusts, (as they try to cope with the impact of the financial crisis on interest rates). Front-line services are likely to be affected or the viability of the organisations may be threatened. Many of the activities and services which older people value are provided by the voluntary and community sector. The consequences of these cuts are as yet not defined but need to be carefully monitored. However it is worth noting that despite this situation, Adult Social Care in Leeds actually increased funding to the Neighbourhood Networks from 2013/14 (£300,000 per year). This is in recognition of their vital role in tackling some of the issues raised above.



6.2 Changes to distribution of local authority funding

There are major changes in terms of how funding is allocated with a move to service commissioning, delivery and provision.

- Local authority commissioning of activity is closely aligned to the developing policy of personalising the health and social care received by adults and older people so that they have more control over the support they receive. This means that money is given directly to older people (and other beneficiaries) who are then able to spend it how they like. Topics include: the growth of personal budgets; co-production with older people (where public service professionals work with individuals, organisations and communities to improve local outcomes). Concerns are growing about rogue traders coming into the market who might take advantage of vulnerable older people, as well as concerns about the ability of older people to manage personal budgets.
- This policy is not only radically altering the nature of care and how it is provided, but it will also transform the role of Adult Social Services in the coming years. Decision-making and control will, increasingly, move away from local authorities and be more determined by local people, or local groups of people. Rather than directly provide services, ASC will co-ordinate the provision of information and advice to people and their carers about the care options available. It will also contribute to the costs of care services - directly or through third parties - where people are eligible for financial support.
- ASC commissioners will be responsible for stimulating and shaping the market for personal care, social care and related housing support services. It will forge new partnerships with health care commissioners and service providers in the voluntary and independent sectors to ensure that a sufficient range of quality services are available at an affordable price to enable real choice. It will also provide intelligence and information to the markets to assist their business planning processes. This should lead to the creation of new business opportunities which is likely to include third sector organisations. However, as with any open market sector, the concern is that local groups may be at a disadvantage compared to larger national private providers who may enter the market place with a potential greater focus on profit than people.



Responsibility for public health has been passed from the NHS to the local Council.

6.3 Changes to health funding

Alongside opening up competition from local Council services, the NHS has also undergone one of the most significant changes in recent decades. Responsibility for public health has been passed from the NHS to the local Council and decisions about allocation of resources are now being made by 3 separate Commissioning Groups covering North, South and East Leeds. There is a concern that this might lead to a two-tier service provision where the old and the poor suffer more. New providers with a need to make a profit, cherry picking of easy treatments as opposed to longer-term conditions, the independence of GP consortia and the needs of older people with complex needs falling between the gaps.

New models of healthcare are emerging where adult health and social care are becoming more integrated. One example is the 12 neighbourhood care teams which including community nursing and social care staff, co-located and working closely with GP's and other professionals in key areas such as mental health. Another is the South Leeds Independence Centre, a new specialist recovery centre offering rehabilitative care managed by the NHS and Adult Social Care. New technology has an important role to play, too with some pilot work being done by health and social care partners around the use of telehealth - technology enabling people to monitor their health at home.



7. WHAT DOES LCF DO?

We have analysed the grants made in 2011/12 and 2012/13 and this reveals we made 118 grants to 78 different organisations specifically supporting working with older people. The total value of these grants was £475,000 although we know grants made to other projects also included older people as beneficiaries.

The largest funder, in terms of value, is the Henry Smith Charity which provided £203,000 in grants of between £20,000 and £30,000 a year to 6 different groups, primarily for salaries. The second key source is Jimbo's fund which tends to give £5,000 to £10,000 a year to the 6 groups in East Leeds working with older people. Jimbo's Fund has invested a total of £130,000 in older people's projects primarily in East Leeds over the past two years. We also accept applications from older people's groups into our other open grants programmes. Over the past two years older people's projects across the City have benefited from £42,000 in funding from the Comic Relief and Sport Relief funds, as well as two larger grants of £14,250 a year for Armley Helping Hands and Caring Together in Woodhouse and Little London.

For the past three years (2011 - 2013) we have run a Winter Warmth campaign. The majority of funding comes from statutory sources but we supplement this by encouraging donations from local people. All the proceeds are then distributed in grants to local community projects supporting older and vulnerable people in Leeds. We have been able to distribute a total of just under £200,000 over the past three years.



8. WHAT CAN YOU DO?

There are many things that local individuals, organisations and companies can do to support the work of community groups working to support older people in Leeds.

- You can send a donation to LCF for our Older People's Fund and we will ensure this is distributed to support work in this area. Or you can specifically support our winter warmth campaign which is usually launched in November. We will, each year, send you a report to demonstrate just what impact your support has had.
- You can set up your own Fund, with a minimum of £10,000 and we will help you find a range of projects to invest in that match your own interests. This may be linked to local geography or specific needs such as dementia or social isolation.
- You can volunteer your time, and that of your staff, to get involved. There are some great partnerships already taking place across Leeds that involve local employees helping: get older people online; befriending and shopping; hosting Christmas parties and making up food hampers.
- Companies can: improve the opportunities for older people in their workplace; raise awareness as being the first step to changing attitudes towards older people, those with dementia etc; you can work with a local older people's group to help your staff better understand some of the issues; send staff on dementia awareness days so they can learn how to take a more positive and tolerant approach.



Thanks

Particular thanks go to Leeds Older People's Forum for assisting with the research and to the following groups for responding with specific examples: Leeds Irish Health and Homes; MAECare; Shantona; Armley Helping Hands; Caring Together in Woodhouse and Little London; Holbeck Elderly Aid; West Indian Family Counselling; Women's Health Matters; Neighbourhood Action In Farnley, New Farnley & Moor Top

Thanks also to Mick Ward from Adult Social Care for sharing (and explaining!) some of the Council's papers on key issues.

Research sources

Age Action Alliance (www.ageactionalliance.org)

Age Action Alliance Working Group: improving the lives of excluded older people

Age UK - Improving Later Life, understanding the Oldest Old

Age UK, Problem Debt Among Older People (produced by the International Longevity Centre UK)

Campaign to End Loneliness, Connections in Older Age

Carers UK, Prepared to Care June 2013

Community Development Foundation - Active at 60

CPS: hate crime and crimes against older people report, 201-11

Joseph Rowntree Foundation: a Better Life - what older people with high support needs value, November 2011

Later Life Newsletter

(www.gov.uk/government/publications/older-life-newsletter-45-june-2013)

Leeds City Council Joint Strategic Needs Analysis 2012 (JSNA)

Leeds City Council's Market Position statement

(<http://www.leeds.gov.uk/docs/LCC%20Market%20Position%20Statement%20%202012.pdf>)

Leeds City Council State of the City Report

(www.leeds.gov.uk/council/Pages/State-of-the-city-report.aspx).

Leeds City Council: Better Lives Leeds

Leeds Older People's Forum: Generations Together in Leeds

Leeds Older People's Forum: Scanning the Horizon, March 2011

Social Care Institute for Excellence, Preventing Loneliness and Social isolation among older people, May 2012

Leeds City Council: Living Well with Dementia in Leeds; Older people as assets; A Dementia-friendly community; co-production with older people; Better Lives through Enterprise.

