

Final Report June 2017

Carers Health Needs Report

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Executive Summary

Background, method and objectives

FMR Research Ltd was commissioned by North Lanarkshire Carers Together (NLCT) to prepare this report to illuminate the health issues carers face and their support needs. This was initiated by the desire to fully analyse the health needs survey undertaken by NLCT over the three years 2013 - 2016 and this data was enhanced by additional qualitative research with both carers and professional stakeholders, plus a brief literature review to set the findings in context.

Context

According to the literature:

- There are an estimated 759,000 carers (17% of the population aged 16+) and 29,000 young carers (4% of under 16s), with 171,000 providing over 35 hours of unpaid care, although the actual number may be higher as carers do not self-identify as carers and things change over time.
- Three out of five carers are female, the most common age group is 55 – 64 and nearly half (46%) have been caring for five years or more.
- Caring affects people in all walks of life, but carers living in more deprived areas were twice as likely to spend more time caring than those in less deprived areas.
- More than 10% of North Lanarkshire's population provide unpaid care (ranked 7th highest out of 32 local authorities, above the Scottish average of 9.3%) and it has the second highest proportion of carers providing 50+ hours of unpaid care per week.
- The estimated value of unpaid care in the UK is £132 billion, which is on a par with the NHS (£134 billion).
- Caring can have significantly negative impacts on a carer's physical and mental health, their short and longer-term income and career prospects. Carers often prioritise the health of the person they care for and do not seek assistance for their own health, which can result in them reaching breaking point (which has repercussions for them and the person they care for). Many carers are also older people, who have their own health challenges.
- Many carers suffer from stress and anxiety, lack of sleep, a deterioration in their own health, inability to seek/attend their own health appointments/treatment because of their caring responsibilities and negative impacts on their relationships, hobbies and social life with little access to short breaks/respite.
- Carers can experience financial hardship given their/the person they care for's inability to work (at all or as much) so income is lower, yet cost of living is often higher.
- 70% of carers report a lack of support. This is perceived to be due to carers' low visibility, carers being unaware of the support available or reluctant to seek/accept it, delays in receiving support even once the need has been identified and the increasing complexity of the caring role.
- The Carers (Scotland) Act comes into force in April 2018 which seeks to legislate for greater recognition and support for carers. However, The Care Act 2016 has similar aims yet the impacts have not been felt by carers as well as might have been hoped. The number of unpaid carers is expected to rise significantly as the population ages and lives longer, so there are calls for support to carers to be increased, and to focus on early intervention and prevention rather than dealing with more costly and harmful crises.

Key findings

Carer profile

- The number of new 'hidden' carers identified each year reflects activity with GP surgeries – those surgeries which engaged well early in the survey show reducing numbers of new carers whilst those who were later to engage have seen increases in the number of hidden carers identified.
- Two-thirds of carers were female and one-third male over the course of the project. Male carers were more likely to be older and caring for a spouse, partner or sibling whilst female carers were caring more equitably across the cared-for groups.
- Carers were represented across the age spectrum, as were those they cared for, but over half (55%) were aged 56+, which is consistent with the national profile, although this did vary by locality.
- 45% of those who gave a view were caring for their spouse/partner, 24% were looking after a parent and 23% were caring for a son or daughter. Whilst most were caring for one person, a handful of respondents were caring for more than one person (9 carers).
- Carers were often caring for a person with more than one health issue. 39% were caring for someone with a physical disability (some of which were tested more specifically) and 20% cared for someone with a mental health issue. There was little variation by gender of carers but older carers were more likely to be caring for someone (most likely their partner/spouse) who was frail elderly and/or Alzheimer's or dementia. Younger carers were more likely to be dealing with pain management, mental health issues, learning disabilities and autism/Asperger's Spectrum Disorder.
- 71% of hidden carers indicated that they spent 50+ hours in their caring role per week, with 9 out of 10 caring for at least 20 hours per week. The amount of time spent caring was greatest for older people – 85% of carers aged 75+ cared for more than 50 hours per week. Those caring for a spouse, partner, sibling or child (80-85%) were significantly more likely to spend at least 50 hours caring than those caring for a parent/grandparent (44%)

Health issues

- Anxiety and stress was the most common health issue identified by carers responding to the survey (75%), although 49% also cited depression/feeling sad and 30% isolation/feeling alone. Those spending more hours per week caring were more likely to indicate being affected by anxiety and stress, as were those who cared for their spouse/partner. Anxiety and stress was consistently the health issue facing most carers in each year of the survey, for North Lanarkshire as a whole and each of the localities.
- The physical impacts of caring were also well-represented, with 44% noting lack of sleep and 36% back pain.
- 27% also noted the financial impacts of caring on their health. This has increased significantly over time, suggesting it has become more of an issue for carers in recent years.
- Older carers were more likely to cite physical health issues (arthritis, 29%; hearing or visual impairments, 10%; and coronary heart disease, 8%) while younger/middle aged carers were more likely to cite mental health issues (anxiety/stress, 81%; depression/feeling sad, 68%; isolation/feeling alone, 34%; and mental health issues, 15%). Younger carers were also significantly more likely to cite (lack of) exercise and being active (42%), lack of sleep (50%), smoking (9%), eating disorders (7%) and the financial impact of caring (35%) than those aged 55+.
- Those spending more time per week caring were more likely to cite anxiety and stress, depression, lack of sleep, isolation and feeling alone, financial impact of caring and mental health issues.

The qualitative discussions reinforced the key messages around carers' health issues identified by the survey, as participants shared their experiences. The report outlines this and quotes participants, to help bring the issues they and others face to life. The challenges of balancing a caring role and managing their own health was highlighted by carers – it can

be difficult to prioritise themselves, even though they know in theory that they need to do so sometimes to be able to continue caring. The Keep Well/carers check up via the GP surgery was perceived to be very helpful in enabling carers to take an opportunity once a year for an 'MOT', and a couple of participants highlighted its role in addressing serious health issues. Carers highlighted that their health needs are often over-looked as many health professionals focus on the cared-for person, even if they have obvious health issues too. However, there was very positive feedback on the support and understanding experienced from North Lanarkshire Carers Together, which was very much appreciated, and a few other organisations were also highlighted positively. Carers felt additional support is required, particularly around respite, financial support, emotional support and better/more information for carers.

Concluding comments

The purpose of this commission was to share North Lanarkshire Carers Together's learning and experience of the health and wellbeing needs of carers. The Carers Health Needs Survey and supplementary qualitative research highlight the widespread, complex and inter-related issues facing carers in North Lanarkshire, and echo the issues identified in the national literature.

There is no doubt that unpaid caring can have a significant short and longer term effect on the health and wellbeing of carers, their quality of life, their relationships, their career and their finances. The Carers (Scotland) Act 2016 will be implemented in 2018 and aims to improve the quality, quantity and consistency of support provided to unpaid carers. A key element of this is the requirement for each local authority to provide an information and advice service for carers. This research clearly supports the importance of an information and advice service for carers. Carers need information and advice in order to exercise greater choice and control over decisions which affect them and those they care for. But there is a critical first step which carers identified: actually being identified as a carer in the first instance. Without being identified as a carer (as many do not think of themselves in this way prior to engaging with NLCT) - and then receiving information, signposting or referral to other services and direct services from NLCT - they could not have accessed any of the support which they had received; and which had made a positive difference to their ability to continue to care and to their own health and wellbeing. This reinforces the importance of working closely with GP surgeries and the need to proactively seek out 'hidden' carers, working in a targeted way to support them.

The positive impacts of annual health checks were also highlighted. These have identified serious health issues for carers and encouraged others to pursue healthier lifestyles and access support to help them do so. A key issue here is the proactive nature of these health checks – when carers are busy and do not prioritise their own health and wellbeing issues, having a reminder to do so via an invitation to attend a health check is very powerful. The fact that this proactive support shows carers that the work they do is recognised by authorities is also very important. Feeling recognised and knowing that they can access support if and when they need to do so – even if they don't access it – makes a big difference to how carers feel about themselves, the role they are playing and the wider 'system'.

North Lanarkshire has a higher than average proportion of carers and is the second highest area in Scotland in terms of carers providing 50+ hours of care per week. It therefore needs to make sure that there is sufficient investment in supporting unpaid carers to stay well and to sustain their caring role, before they hit crisis point. North Lanarkshire is not starting from scratch here as it has excellent, established carer support agencies, such as the NLCT team who are working with GPs to identify hidden carers and link them into a range of supports. The public sector in North Lanarkshire also has an excellent track record of incorporating carers' issues into strategies, policies and strategic structures so the carer's voice is heard. But there is still some way to go, so it is hoped that support for carers is protected from budget pressures and built upon in the lead up to the implementation of the Carers (Scotland) Act next year, to ensure North Lanarkshire's response is equal to the challenges facing its legion of unpaid carers

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1 Introduction

1.1 This report

This report outlines the findings from a three-year survey of the health needs of new or previously 'hidden' carers and some supplementary qualitative research with carers and health or carer professional stakeholders, to help illuminate the health issues carers face and their support needs.

1.2 Context

Scale and profile of carers

Unpaid carers – people looking after family members and/or friends who have an illness or disability – are an extensive but often unrecognised resource. There are an estimated 759,000 adult carers (17% of the population aged 16+) and 29,000 young carers (4% of under 16s) in Scotland¹, with an estimated 171,000 carers aged 16+ providing 35 hours or more unpaid care per week in Scotland. This is a snapshot in time, so many more people will provide unpaid care at some point in their lifetime. Scotland's Carers 2015² profiles unpaid carers using the 2011 Census and 2012/13 Scottish Health Survey, although it recognises that there are inherent difficulties in doing so as many carers, particularly women, do not see themselves as carers – it is just part of what they do as a daughter, partner, mother, sister or friend to look after the people they care about. The 'official' figures are therefore likely to under-estimate the number of carers. Three out of five carers are female, the most common age group for carers is 55 – 64 and nearly half (46%) had been caring for five years or more.

Whilst there is little difference in terms of the incidence of carers according to the Scottish Index of Multiple Deprivation (SIMD), carers in more deprived areas were twice as likely to spend more time caring than those in less deprived areas. Younger people in more deprived areas were also more likely to be carers and to spend more time caring than their less deprived counterparts. More than 10% of North Lanarkshire's population provide unpaid care (ranked 7th out of the 32 local authority areas, so above the Scottish average of 9.3%) and it has the second highest proportion of carers providing 50+ hours of unpaid care per week when the data is considered by intensity of caring.

It has been estimated that the value of unpaid care in the UK is £132 billion, on a par with spending on the National Health Service (£134 billion)³. This may seem a remarkable statistic but given the number of hours many carers spend caring for their loved ones – for some it is a 24/7 role and many provide care for more than 50 hours a week – and the number of carers, value can quickly accumulate. This fantastic resource and contribution from carers is not currently consistently recognised and/or well-supported across the country and this presents a considerable risk to the ongoing ability of carers to provide the same level of care, not to mention the impacts on their own health and wellbeing. Many carers want to look after their parents, partners, children or friends but, for some, this can involve them sacrificing their own work/study, hobbies and interests, relationships, health and wellbeing.

¹ Scotland's Carers 2015 <http://www.gov.scot/Resource/0047/00473691.pdf> accessed 15 May 2017

² Scotland's Carers 2015 <http://www.gov.scot/Resource/0047/00473691.pdf> accessed 15 May 2017

³ Carers UK, the University of Sheffield and the University of Leeds (2015) Valuing Carers 2015 – the rising value of carers' support <http://www.carersuk.org/for-professionals/policy/policy-library/valuing-carers-2015> accessed 1/5/2017

Health impacts of caring

The Scotland's Carers 2015 report suggests that some caring can be rewarding and beneficial but too much, particularly for those in more deprived areas, can have negative consequences for carer health and wellbeing, with carers who spend more time caring being more likely to describe their health as bad or very bad. 41% of carers said they had a long-term condition or illness and this increased with caring input. Young carers aged under 25 were also twice as likely as non-carers to have a long-term condition or disability (22%). Poorer physical health was also associated with old age, challenging care situations, lower economic status and less informal support and caring may impact on a carer's ability to look after their own health. Poor carer health was found to have lasting impacts on the carer which can continue after the caring role has stopped. Carers are also more likely to have long-term mental health issues and unpaid caring is a significant predictor of poor mental health and wellbeing and possible psychiatric disorders⁴, particularly for those providing higher levels of care over extended periods, those living with the cared for person and female carers.

Carers UK's State of Caring Report 2016⁵ highlights that one in five carers providing 50 hours or more of care each week were receiving no support with their caring role. Without support, carers can be pushed to breaking point and have to stop caring, stop work, or have serious physical and/or mental health challenges themselves. However, this is complex as carers also often do not want the person they care for to know the impact caring has on them, so can cover up their own health issues because of that. Carers UK's Carers at Breaking Point⁶ report highlights the following findings from a survey of over 5,000 carers:

- 6 out of 10 carers who responded have been pushed to breaking point;
- a quarter of those who had reached breaking point required medical treatment as a result;
- 90% of those who had reached breaking point were stressed, compared to just over half of those who were not in crisis;
- 8 out of 10 (79%) reported anxiety compared to under half of carers who said they were coping;
- 75% said they could not get a good night's sleep (compared to 50% of carers who had not reached breaking point);
- half (50%) had suffered a physical injury or seen a deterioration in their own health;
- almost half (46%) said they had fallen ill but just had to continue caring;
- 2 out of 5 said they had been forced to put off treatment because of their caring responsibilities because they were unable to find suitable and affordable replacement care or get flexibility from the NHS to access health services around their caring responsibilities;
- 1 in 9 said the person they cared for had to be hospitalised or social services had to step in to look after them while the carer recovered; and
- 1 in 5 were forced to give up their jobs because they were in crisis.

A caring role can have significant impacts on carers' physical health, particularly because of the hands-on nature of caring for someone who needs to be helped to move, the impact of too little or interrupted sleep (from helping the person they care for to go to the toilet, to take medication, to turn them or respond to any other need) and the stress and anxiety of caring. This is present for nearly all carers, but can be particularly challenging for those caring for people with mental health issues, learning disabilities or cognitive conditions as they need to be 'on duty' all the time and cannot relax. Caring duties can mean that it is very difficult for carers to leave their home, increasing their social isolation and further impacting on their health and wellbeing. The Carers at Breaking Point report cites the GP Patient Survey 2013

⁴ using the Warwick-Edinburgh Mental Wellbeing Scale and General Health Questionnaire in the Scottish Health Survey, reported in Scotland's Carers 2015

⁵ <https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2016> accessed 1/5/2017

⁶ <https://www.carersuk.org/for-professionals/policy/policy-library/carers-at-breaking-point-report> accessed 1/5/2017

which shows that while 51% of non-carers had a long-standing health condition this rose to 60% of all carers and 70% of carers caring for 50+ hours a week. This included significantly higher levels of arthritis, high blood pressure, long-term back problems, diabetes, mobility problems, anxiety and depression. Without time to recover and seek treatment, these conditions can escalate.

Sleep has been increasingly recognised to be vital to our health and wellbeing⁷, as it allows our bodies to repair themselves and our brains to consolidate memories and process information, so that we can function properly during the day. Poor quality and lack of sleep has been linked to a variety of health problems, including weakened immune system, mental health problems such as anxiety and depression as well as the more obvious fatigue, sleepiness, lack of energy, poor concentration, lapses in memory and increased irritability or low mood. Indeed, poor sleep can increase the risk of poor health and poor health can make it harder to sleep – it's a two-way street. People who work night shifts are thought to be at greater risk of cancer and heart disease so carers may also be affected by this if their sleep is too short, interrupted or otherwise of poor quality. Deep sleep is particularly important in helping the brain to consolidate learning from the day and is a refreshing type of sleep. If wakened during deep sleep, people feel groggy and disoriented. Sleep Matters suggests that people who suffer from anxiety may spend less time in deep sleep, so do not benefit from its restorative properties. It also reports that dreaming and REM (rapid eye movement) sleep are also strongly related to depression – people with depression often dream more and have more REM sleep, plus too much REM sleep can make people more vulnerable to depression.

Financial impacts of caring

Despite the sizeable contribution carers make to the health and care system, they are not protected from financial hardship. Caring (a role which is often adopted suddenly if a loved one becomes ill) often results in a reduction in household income (in the short and longer terms because of pension implications), through the inability of both the carer and cared for person's inability to work at all or full-time. Carer's UK 2014 Caring & Family Finances Inquiry highlights that carers also face higher utility bills (as they are at home more, they do more laundry and the house needs to be warm), higher transport costs (taxis are often required as the cared for person cannot take the bus or train to hospital appointments, etc.), higher shopping bills (specific food/drink may be required, cleaning products, continence products, etc.), some aids and adaptations or care support may be charged for⁸. As a result, 44% of carers are reported in this inquiry to be struggling to make ends meet, rising to nearly half (48%) of those caring for 35 hours per week or more. In addition, a quarter (26%) of carers reported that they are or have been in debt due to their caring role. This financial hardship results in carers cutting back on essentials (food, heating, utility bills), using savings, borrowing money (credit cards, loans or from friends and families) and not seeing friends and family as often (which increases isolation). Three-quarters of carers (73%) of those struggling to make ends meet reported that worry about their finances was affecting their health.

The 2011 Census shows nearly 172,600 people provided 35 hours or more care each week, the threshold for carer's allowance. Department for Work and Pensions (DWP) data show that in 2014 104,000 who applied for carer's allowance were entitled to it and approximately 59,000 people actually received it. Carers aged 65+ are most likely not to receive carer's allowance if they are already receiving pension credit.

The State of Caring Report 2016 also provides a sense of the impact of caring in the working environment: 1 in 9 people in the workforce have a caring role too, but many colleagues and managers do not understand the issues they face. This report highlights that carers seek understanding and flexibility at work in addition to affordable care services that give them peace of mind that the person they care for is well looked after. If this is not the case,

⁷ <https://www.mentalhealth.org.uk/publications/sleep-report> accessed 1 May 2017

⁸ <https://www.carersuk.org/for-professionals/policy/policy-library/caring-family-finances-inquiry> accessed 1/5/2017

however, it can increase their stress, anxiety and isolation and can lead to them reducing hours, taking lower paid work or not progressing their careers (17%) or even giving up work (49% had given up work to care). The fact that 70% of carers have used their annual leave to care and half (48%) have had to do overtime to make up time spent caring illustrates the strain of working and being a carer. Two-thirds (67%) of those who had given up work, retired early or reduced their hours said that stress of juggling work and care was a contributing factor and 31% that there were no suitable care services. 16% said that leave available from work was not sufficient to enable them to manage caring and work, and 18% were unable to negotiate suitable working hours.

Support for carers

Scotland's Carers 2015 highlights the lack of carer support: the Scottish Health Survey 2012/13 shows that 70% of carers said they received no support with their caring responsibilities. The likelihood of support did increase with the number of hours of care provided, but 42% of carers providing 35 hours or more of care still said they did not receive any support. In addition, the Scottish Government's 2013/14 Health and Care Experience Survey 2014 revealed that at least one in five carers were not sufficiently supported to continue caring. The report highlights a number of contributory factors: the low visibility of carers, carers being unaware of available support, plus delays in receiving support and practical assistance once identified – for some it came after a crisis had already occurred. Carers themselves may also be reluctant to see support externally, for a variety of reasons.

Macmillan Cancer Support⁹ also highlights the growing number of cancer carers who spend more time providing complex caring despite being older and experiencing their own health and wellbeing issues, pressures on their working life and finances and with little recognition and support from health and social care professionals. Macmillan highlights that over half (55%) of people who care for someone with cancer do not consider themselves to be a carer and more than a third (36%) have not been recognised as a carer by any health or social care professional (40% of female cancer carers compared to 29% of males). If carers do not recognise themselves as carers and are not recognised as carers by others, they are at risk of not accessing the emotional, financial and practical support they need to continue caring.

Macmillan cites two-thirds of cancer carers would benefit from more help and support, with 55% not receiving any kind of support for themselves – 67% of those who have not been identified as carers by others. A quarter (27%) of those who lacked support said this was because they did not know what support was available, they could not afford it or they did not have the time to look for it or make use of the support, reinforcing the role of information and signposting services. The Macmillan report calls for greater collaboration between government bodies, health and social care professionals, the voluntary sector and carers to help ensure carers access the support they need to continue caring.

The State of Caring Report 2016 suggests that more support from care workers in-home, support with household chores such as shopping and support to manage or co-ordinate care were the three issues which would help carers to stay in full employment. Over half (54%) of carers surveyed for that report expect their quality of life to get worse in the next year, with just 6% expecting it to improve.

The above context illustrates that caring can have a significant negative impact on carers' physical and mental health and wellbeing. Short breaks (respite care which is designed to achieve positive outcomes for both carer and cared for person) are considered to be critical to help mitigate against the negative impacts of caring. A 2012 study around short breaks¹⁰ found that over half of survey respondents (57%) had not taken a break from caring, and this was even higher for BME carers (63%). Where people had taken a break, they were satisfied with the quality of break, choice available, support to organise it and the length –

⁹ <https://www.macmillan.org.uk/documents/campaigns/under-pressure-the-growing-strain-on-cancer-carers-macmillan-cancer-support-september-2016.pdf> accessed 1 May 2017

¹⁰ <http://www.sharedcarescotland.org.uk/wp-content/uploads/2015/02/iriss-rest-assured-summary-2012.pdf> accessed 1 May 2017

the key issue was around frequency of breaks. 43% of those who had not had a break did not know how to access short breaks. Carers suggested that short breaks should be provided as an early intervention rather than at crisis point, with greater choice (including culturally sensitive services for BME carers), flexibility, frequency and length of short breaks. Information about carers' entitlements and the availability of short breaks is critical, and better planning processes were also cited, including a single point of contact and the ability to secure short breaks well in advance.

The Carers (Scotland) Act comes into force in April 2018, however, which seeks to legislate for greater recognition and support for carers. However, the aspirations of the legislation and how well it is enacted are two different things. The Care Act 2014 in England introduced in 2015 was designed to make it easier for carers to be assessed and supported, as the Scottish Act also aims to do. The State of Caring Report 2016 showed that only a third (35%) of carers who had an assessment in the previous year felt the support they needed to look after their own mental and physical health alongside their caring role was properly considered. A similar proportion (29%) of those who had been offered or had asked for a carer's assessment had waited more than six months or were still waiting six months later. One in five (21%) of those who had an assessment said they received little or no helpful information or advice and felt they did not know where to go for support with caring. A further 45% got some but not all the information they needed (suggesting a maximum of a third did get what they needed). The State of Caring Report 2016 therefore calls for the following:

- Improving financial support so carers and their families do not suffer financial hardship as a result of caring.
- Greater investment in social care and health funding so that new legal rights for carers are adequately financed.
- Improving carers' health by placing a duty on the NHS to identify carers and make services more carer friendly, with increased funding for carers' breaks.
- Strengthening rights for carers in employment, with more statutory rights to time off work to care.

The Manifesto for Unpaid Carers in Scotland¹¹ is produced by seven national carer organisations who share the vision that *"all unpaid carers will be valued, included and supported as equal partners in the provision of care and will be able to enjoy a life outside of caring"*. This states that the number of carers in Scotland is likely to increase to 1 million carers within twenty years. It calls for the following:

1. Adequate resources to implement the Carers Act so that local authorities can invest new and existing resources in carer support to realise the preventative aim of the legislation and not just support carers in crisis.
2. Increased efforts to improve short break provision as essential and valued services to help carers' health and wellbeing and to sustain their caring role, with minimum entitlement to breaks from caring.
3. Better, preventative support for carers, including adequate funding of local carer support organisations to cope with increasing demands.
4. Improved financial support for carers.
5. Sufficient, sustainable funding for social care recognising the growing number of people needing care/carers and recent cuts to care services. Long-term, sustainable solutions need to be considered.
6. Supporting carers in and into employment, because of the reduced income (in the short and longer term) for carers and impact on the economy. This might include 'Carers Leave Employer' accreditation where 5 – 10 days paid leave per year can be taken for caring duties; specialist childcare is available to families of disabled children (including during the summer); and develop an employability programme for carers.

¹¹ <https://www.carersuk.org/news-and-campaigns/news/manifesto-for-unpaid-carers-in-scotland-published> accessed 1 May 2017

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7. Introducing health checks for all carers, for example the carers' register in GP practices should trigger an offer of a health check appointment every six months to see if additional support is required to protect the carers' own health and wellbeing.

Existing statistics and carer feedback therefore suggest that there are significant numbers of carers, many of whom are not identified as such to services, who provide substantial amounts of unpaid care and this can have a huge impact on their own physical and health and wellbeing, their employment and their financial circumstances, amongst other things. This report aims to provide additional context to carers' experiences in North Lanarkshire.

1.3 Background to this study

From April 2013 to March 2016, North Lanarkshire Carers Together (NLCT) undertook a Carer Health Needs Survey as part of the team's work in GP practices. This is spear-headed by Yvonne Cameron and Corinne Thomson, who are both Co-ordinators for Carers, Primary Care (North Lanarkshire). These posts are funded by Scottish Government Carer Information Strategy monies and they report quarterly to the NHS Lanarkshire Carer Information Strategy Group. Yvonne and Corinne work within North Lanarkshire's 64 GP practices to identify hidden carers and assisting via practice staff training and liaison, provision of Carer Information Packs, augmenting the GP Carers Register, plus updating staff and notice boards in each practice with relevant information. The team engage with carers and signpost and/or refer them to appropriate services as required.

For three years, when a 'new' carer (i.e. one who hasn't been identified as a carer before, even though they may have performed a caring role for some time) was identified by the team, they were also asked to complete a Carers Health Needs Survey form. This was completed anonymously and returned by reply-paid envelope. A total of 1,267 forms were returned in the three years the survey was live, with around 400 per annum, so there is a robust data source for analysis. NLCT was keen to maximise the value of this resource by commissioning additional primary research, analysis and reporting, to help provide fuller and evidenced insight into the health issues of carers in North Lanarkshire. This is the subject of this report.

It is hoped that this insight will be utilised at both strategic and operational levels by a wide range of local and national organisations, as there is a dearth of hard data on the health needs of carers particularly over time and with a robust sample.

1.4 Objectives

The purpose of the commission was to share NLCT learning around the health needs of carers. By initiating fuller analysis of the Carers Health Needs Survey 2013-2016 data set, augmenting this with primary research and placing this in the context of external literature, NLCT hope to provide clarity on the health issues carers face.

2 Method

The research included three key elements:

1. analysis of the NLCT Carers Health Needs Survey dataset;
2. contextual positioning; and
3. primary research with carers and professional stakeholders.

2.1 Analysis of the NLCT Carers Health Needs Survey dataset

The NLCT team input the data from the survey returns onto an Excel spreadsheet and FMR exported the data into SPSS for coding and analysis. The survey data is presented in graphical form in the following section, broken down by geographic area or demographic groups where appropriate. A written commentary is also provided to describe the data.

2.2 Contextual positioning

Limited desk research was undertaken to help 'join the dots' and place the data in the wider evidence context. A number of sources were reviewed, including the following:

- Sleep Matters: The Impact of Sleep on Health & Wellbeing
- State of Caring Report (2016)
- Carers at Breaking Point (2014)
- Carers and Family Finances Inquiry (2014)
- Rest Assured – Short Breaks Report (2012)
- Carers (Scotland) Act 2016
- Scotland's Carers (2015)
- Manifesto for Unpaid Carers (2016)
- Under Pressure – The growing strain on cancer carers (2016)
- Valuing Carers 2015 – the rising value of carers' support

2.3 Primary research

Primary research was conducted to help illuminate the secondary data analysis. Two focus groups were completed: one with carers (4 participants) and one with professional stakeholders (3 participants) who were also carers. Two depth interviews were also completed, one with Dr Calder, a GP in Motherwell and one with a carer who was unable to attend the focus group because of health issues on the day.

Whilst just a small sample of carers were included in the qualitative research, they included carers caring for parents, partners and children/grandchildren, some carers caring for more than one person in different generations, carers who work and those who do not. Participants cared for people with different health conditions, including COPD, diabetes, cancer, Asperger's/autism, ADHD, epilepsy, learning disabilities and dementia. Just one carer included in the qualitative research was male, with the remaining 8 being female.

Two of the three professional stakeholders who participated in the focus group worked for North Lanarkshire Carers Together (one as Co-ordinator for Carers – NHS Primary Care and one Community Link Worker/Carer Information Officer) plus the Carer Co-ordinator for Mental Health, NHS, who worked closely with NLCT during the time of the carers health needs survey.

Dr Calder's practice has been providing enhanced carers support for some time and has worked with the NLCT team to do so. For example, they have a carers' database, issue 'someone relies on my care' cards, give priority to carers for appointments with more flexibility over timing, liaison with NLCT, carers are invited in for an annual health check, have information in reception to help identify hidden carers (a carers' table of information), reception staff have been on Carers' Champion training, they can phone the Practice Manager directly if they have any issues or questions, the fact that they are a carer pops up on their patient notes and Monday evening surgeries are provided after 6pm as this suits some carers better. They have also had Carers' Days where carers are invited in and half the waiting room is blocked off and various information and services provided (such as tea/coffee, massage, talks about benefits, etc.). These have been well-attended and the event has also prompted others to sign up for the carers database/card. The surgery has also looked at the health survey and needs of carers, such as poor sleep, to consider what they can do to help self-management of these issues and what medication may be of assistance.

A topic guide was designed to structure discussion to some degree. There was overlap between areas explored in the survey, such as health issues carers face, plus additional questions, such as working carers' experiences of support from employers and peers. The findings from the primary research are therefore interwoven with the survey data, to help illuminate the issues more fully.

3 Key findings

3.1 Introduction

The Carers Health Needs Survey, which was conducted by NLCT for three years (April 2013 – March 2016) was relatively short – just two sides of A4. It gathered profiling information on the carer and cared for and sought feedback on the key health issues carers were experiencing and the support they felt was required. This section starts by outlining the findings from the survey, following the flow of the questionnaire. The latter part of the section also incorporates the findings from the focus groups and depth interviews, to help provide more insight to the issues facing carers and bring the data to life. Where appropriate, contextual comments from the literature have been included to support the local perspectives gathered.

It should be noted that this was a self-completion survey so not every respondent gave an answer to every question. The base (number responding) for each question is noted in each chart. Any percentages quoted are subject to rounding, so may not total to precisely 100%.

3.2 Profile of survey respondents

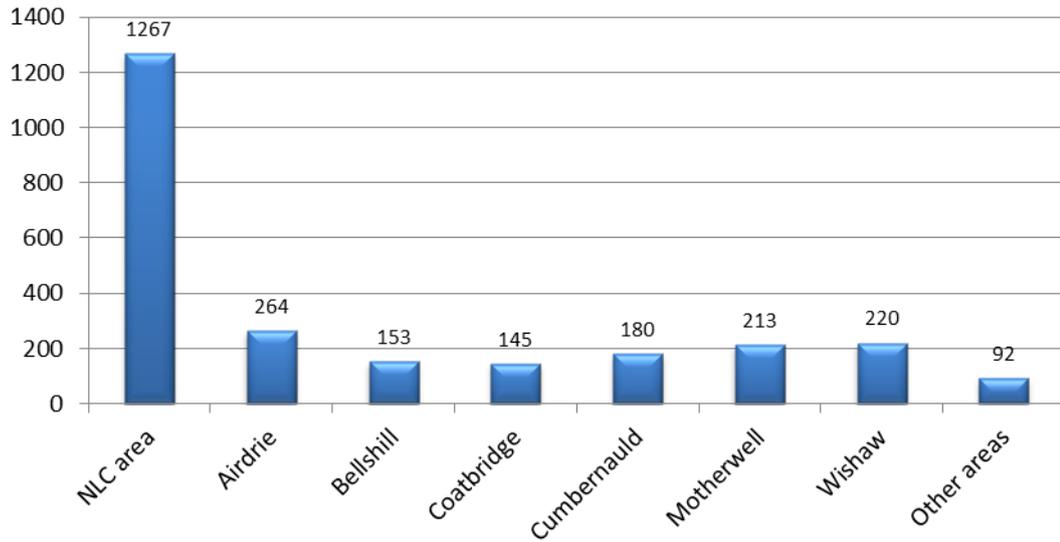
3.2.1 Areas of North Lanarkshire

NLCT broke responses down into 7 geographic areas: Airdrie, Bellshill, Coatbridge, Cumbernauld, Motherwell, Wishaw and other. A total of 1,267 carers responded to the Carers Health Needs Survey and the absolute number of respondents by area is shown in the figure below. A good spread of views was therefore captured across North Lanarkshire over the life of the survey.

The split of responses by area is as follows:

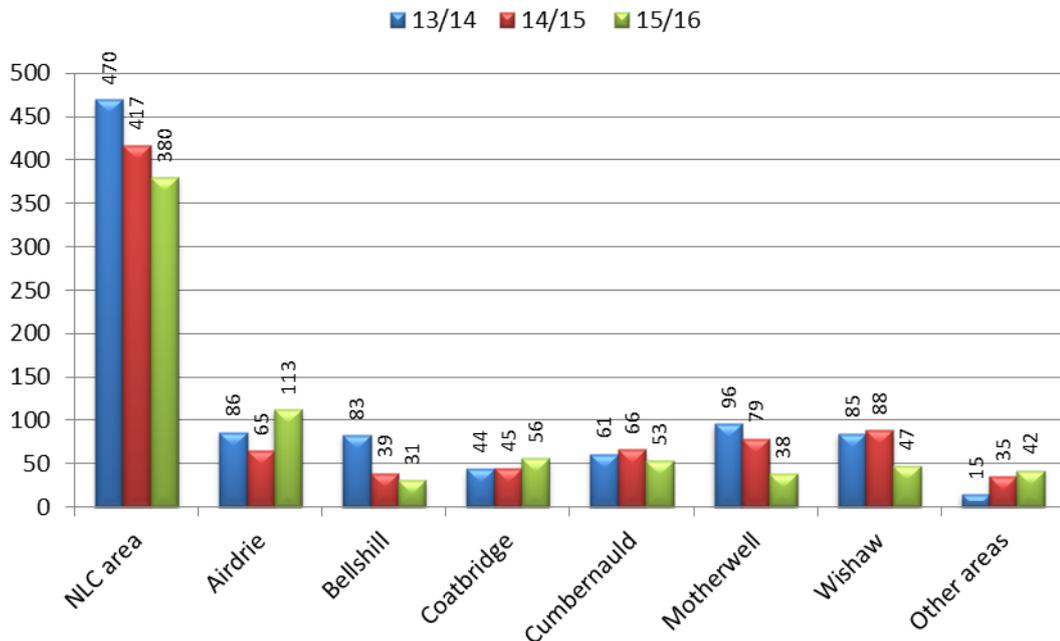
- 21% (264 respondents) from Airdrie;
- 17% (220 respondents) from Wishaw;
- 17% (213 respondents) from Motherwell;
- 14% (180 respondents) from Cumbernauld;
- 12% (153 respondents) from Bellshill;
- 11% (145 respondents) from Coatbridge; and
- 7% (92 respondents) from other areas.

Figure 1 All respondents by area



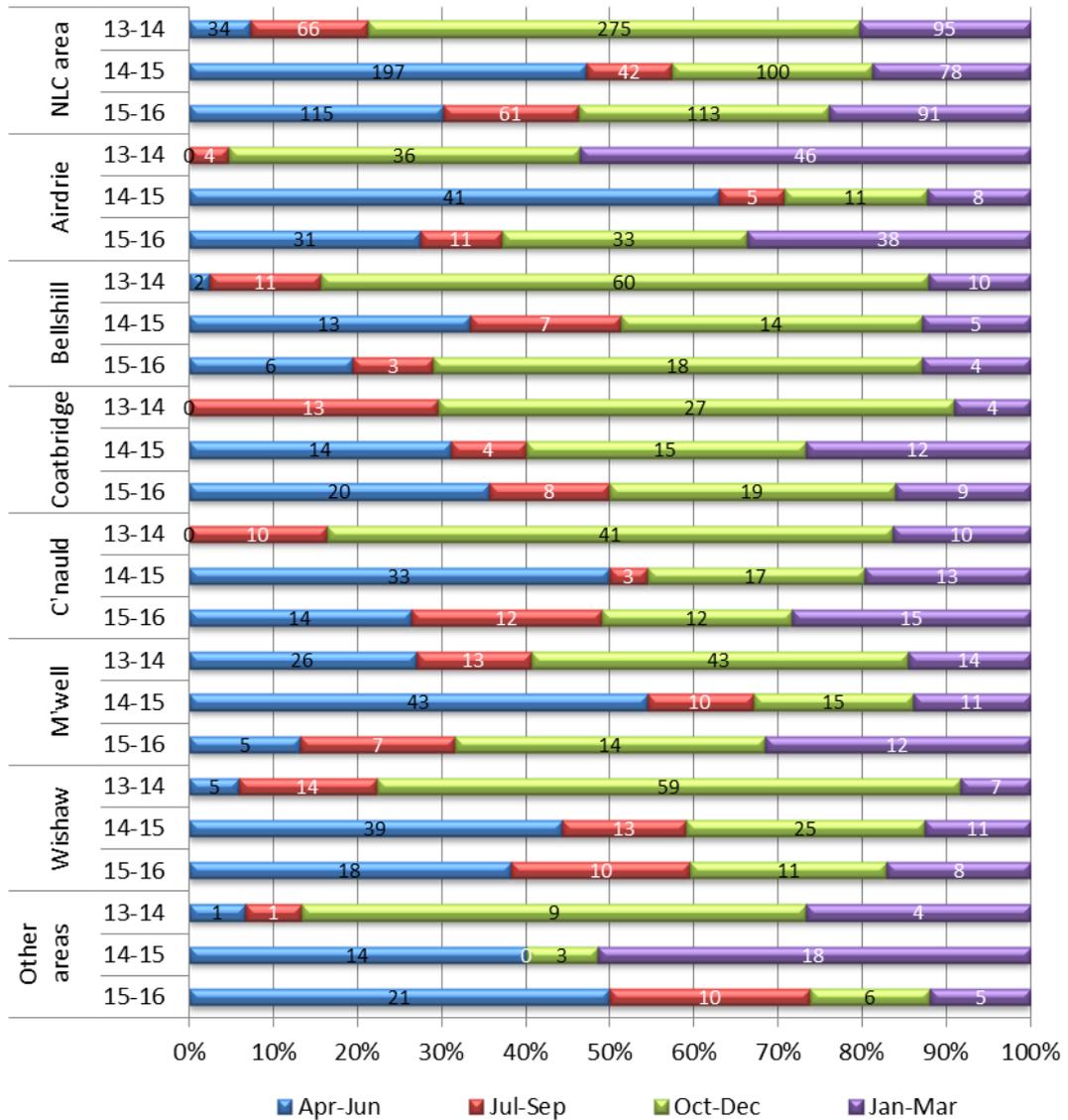
The figure below shows the number of carers responding to the survey in each year it was undertaken, for North Lanarkshire as a whole and by area. Whilst, as might be expected, the number of ‘new’ carers responding showed a slight decline year on year since the start of the project, more ‘new’ carers in 2015-16 than in previous years gave their views in three areas – Airdrie, Coatbridge and ‘other areas’. In contrast, numbers dropped particularly sharply in Bellshill (from 83 in 2013/14 to 31 in 2015/16) and Motherwell (from 96 in 2013/14 to 47 in 2015/16). This perhaps reflects the degree of liaison with GP surgeries across the three years of the survey and, most importantly, the successful conversion of this activity into identification and referral of hidden carers to NLCT.

Figure 2 Respondents per year by area



The figure below breaks down the number of respondents in each area for each quarter of the three years the survey was undertaken. It shows there is no set pattern to when hidden carers are identified, as it varies in each year.

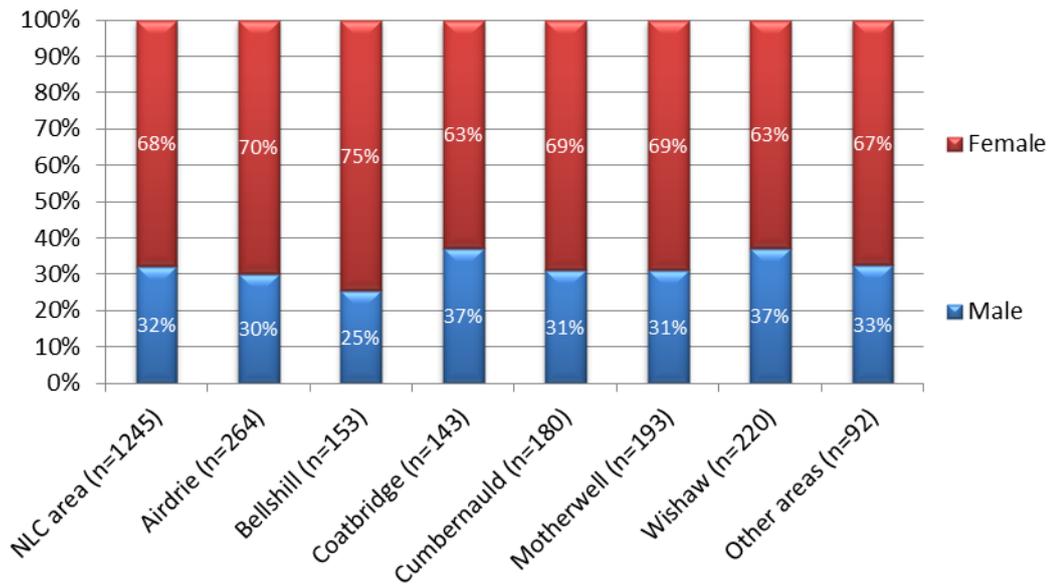
Figure 3 Participants, quarterly breakdown by area



3.2.2 Gender of carers

As would be expected given the national profile of carers, the proportion of females in a caring role was much higher than males with about two-thirds of carers being female (68%, 845 females) and one third male (32%, 400 males), over the course of the project. This proportion was fairly consistent across the areas, although Bellshill had a slightly higher proportion of female carers at 75% (114 female carers) than other areas.

Figure 4 Gender



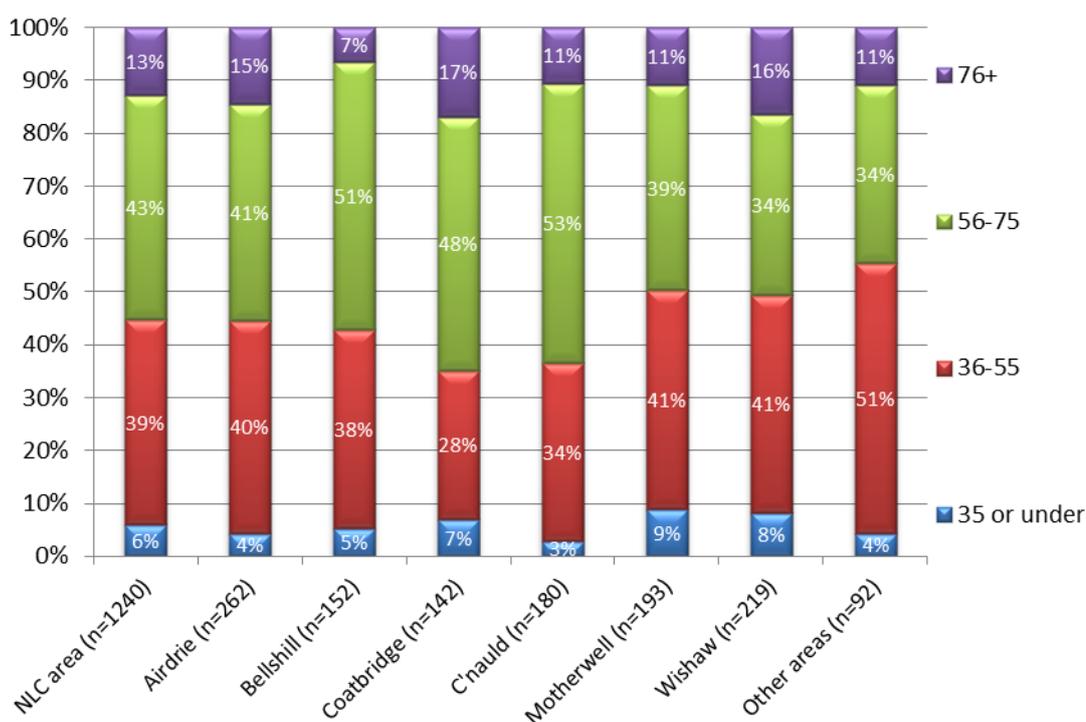
Over the period of the project, fewer male carers were identified in 2013/14, compared to 2014/15 (29% in 2013/14; 37% in 2014/15).

Those carers aged 56+ were more likely to be male than younger carers (36% of 56+ were male carers compared to 28% of those aged 55 or under). Similarly, a higher proportion of those looking after a spouse, partner or sibling were male (43%) compared to those looking after a parent/grandparent or child (both 21% males). Three out of five (61%, 244 respondents) of male carers who responded to the survey were caring for their partner/spouse, whilst female carers were more evenly spread across the different cared for groupings.

3.2.3 Age of carers

As might be expected, carers were represented across the age spectrum, reflecting the fact that people care for parents, partners, siblings, friends, children and other relatives, as required, and some carers may be caring for more than one person. Over half of carers were older (55%, 686 respondents, were aged 56+), as per the national profile, with Coatbridge and Cumbernauld having a higher proportion of older carers (65%, 92 respondents, and 63%, 114 respondents, respectively were aged 56+) than other areas. 13% of respondents (158) across North Lanarkshire were aged 76 plus, varying from 7% (10) in Bellshill to 17% (24) in Coatbridge. Just 6% (73) were aged 35 or younger, varying from 3% (5) in Cumbernauld to 9% (17) in Motherwell.

Figure 5 Age



A higher proportion of those looking after a spouse, partner or sibling were aged 56+ (75%, 426 respondents) compared to those looking after a parent/grandparent or child (37%, 103 respondents, and 36%, 97 respondents, respectively aged 56+). Those caring for a child were largely aged 36 – 45 (29%, 77 respondents), 46 – 55 (26%, 70 respondents) and 56 – 75 (30%, 80 respondents). Those looking after parents or grandparents were most likely to be aged 46 – 55 (40%, 114 respondents) or 56 – 75 (35%, 100 respondents).

Those who gave their views in 2013/14 were slightly more likely to be older (60%, 268 respondents, were aged 56+) compared to later years (51%, 213 respondents, in 2014/15 and 54%, 205 respondents, in 2015/16 were aged 56+).

3.2.4 Ethnicity

Only 3% of respondents (31 carers) over the course of the project who disclosed their ethnicity were of an ethnicity other than Scottish (88%, 1,111), English (1%, 18), British (0%, 5) or Irish (0%, 2). Two-thirds of these responded in 2013/14 (20 carers). Although numbers in each area were small, Motherwell (11) and Cumbernauld (8) had the highest number of minority ethnic carers. However, it should be noted that 100 people (8%) did not share this information.

3.3 The caring role

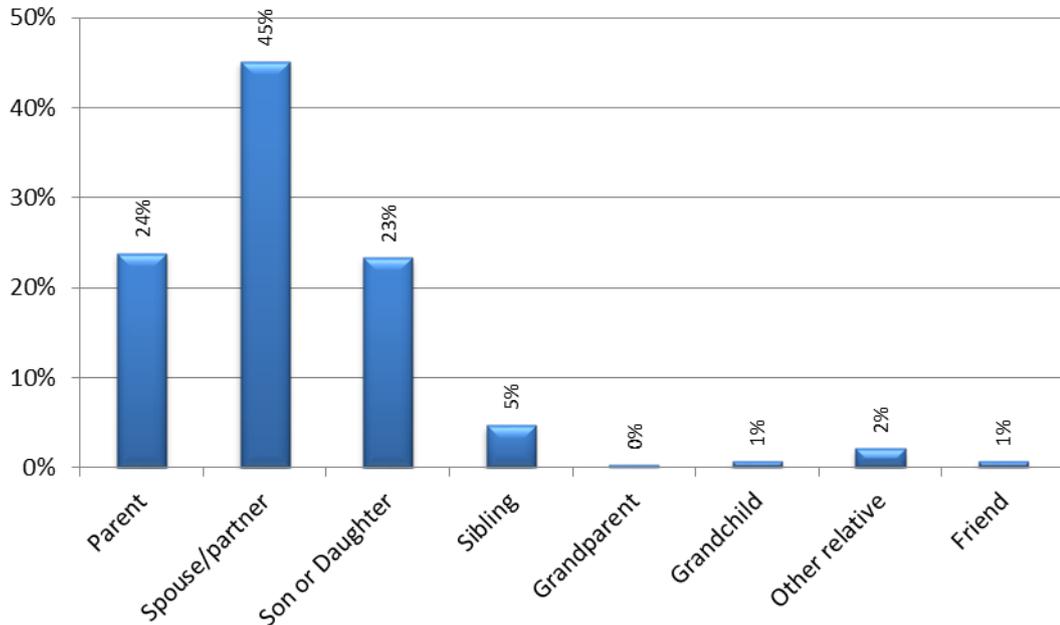
3.3.1 Who were carers caring for?

Nearly half of the carers responding to the survey who gave a view (45%, 532 respondents) were caring for their spouse or partner. A quarter of carers (24%, 281 respondents) were looking after a parent and a similar proportion (23%, 275 respondents) were looking after a child. Just 5% (55 respondents) were caring for a sibling and the remaining few percent were caring for a grandparent, grandchild, other relative or friend. 7% of respondents (88) did not provide this information.

Some carers were caring for more than one person, for example:

- 6 of those caring for a spouse or partner were also caring for a child;
- 2 of those caring for a parent were also caring for a sibling; and
- 1 person caring for a parent was also caring for a child.

Figure 6 Who do you care for – NLC area?



n=1,179

Whilst just a small sample of carers were included in the qualitative research, they included carers caring for parents, partners and children/grandchildren, some carers caring for more than one person in different generations, carers who work and those who do not.

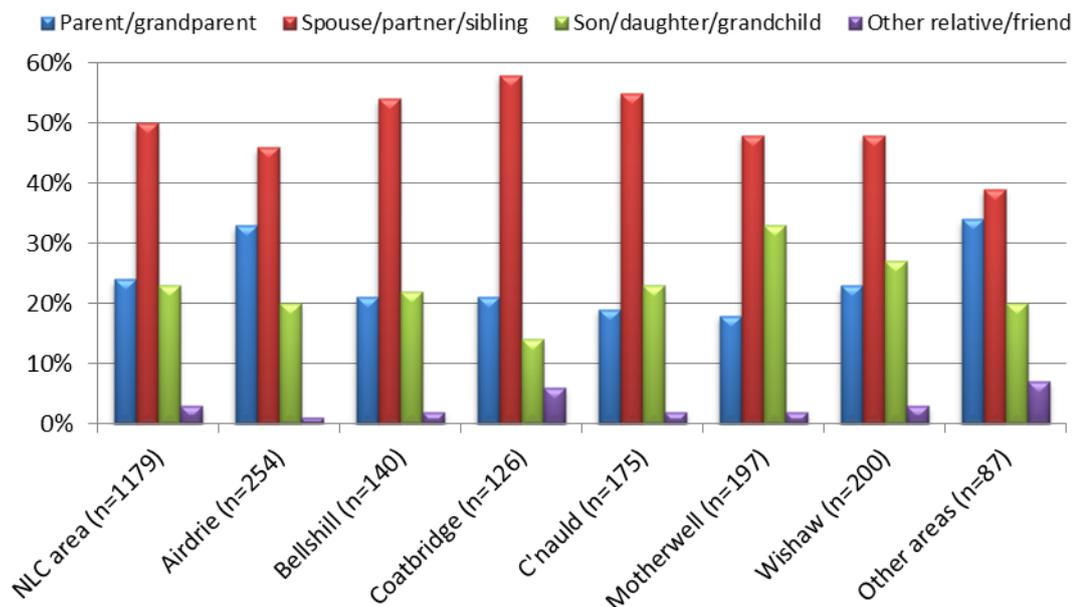
The profile of the people cared for by survey respondents varied over North Lanarkshire. Carers were significantly more likely to be looking after parents/grandparents (only 4 were looking after grandparents) in Airdrie (33%, 84 respondents), whilst this was lowest in Motherwell (18%, 35 respondents) and Cumbernauld (19%, 34 respondents). The proportion of carers looking after a child or grandchild was significantly higher in Motherwell (33%, 65 respondents) compared to Coatbridge (14%, 18 respondents) and Airdrie (20%, 50 respondents).

The proportion of carers caring for a parent or grandparent in 2014/15 (26%, 96 respondents) and 2015/16 (31%, 117 respondents) was significantly higher than in 2013/14 (17%, 72 respondents). In contrast, the proportion of carers caring for a child/grandchild in 2013/14 was significantly higher in 2013/14 (30%, 129 respondents) than in 2014/15 (20%, 73 respondents) and 2015/16 (20%, 74 respondents).

As outlined above, female carers were significantly more likely to be caring for parents/grandparents (28%, 223 respondents) and children/grandchildren (27%, 215 respondents) than male carers (16%, 60 respondents, and 15%, 56 respondents respectively). However, male respondents were consequently significantly more likely to be caring for their spouse, partner or sibling (66%, 244 respondents) than females (42%, 330 respondents), who were caring more equitably across the cared for groups.

As might be expected, older respondents were significantly more likely to be caring for a spouse, partner or sibling than either a parent/grandparent or child/grandchild

Figure 7 Who do you care for – local areas?



3.3.2 Health issues of cared for person

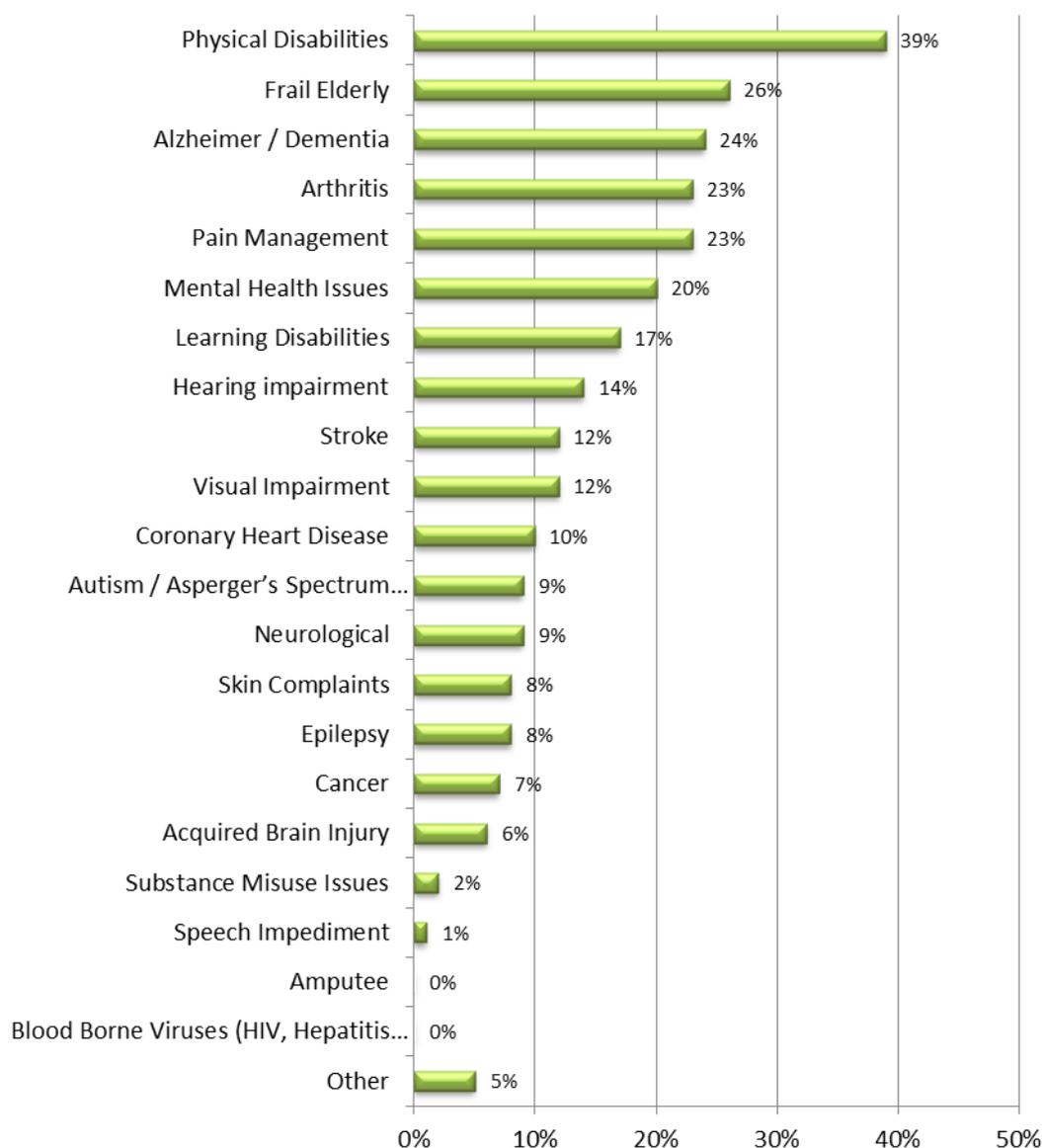
The survey also asked carers about the health issues of the people they care for and it should be noted that often several issues were noted. Physical disabilities were the most commonly cited health issue (39%, 481 respondents), which obviously covers a wide range of health issues, some of which were also asked more specifically. For example, a number of health issues were common age-related conditions, such as frail elderly (26%, 313 respondents), Alzheimer's/dementia (24%, 297 respondents), arthritis (23%, 281 respondents), hearing impairment (14%, 172 respondents), stroke (12%, 147 respondents), visual impairments (12%, 147 respondents) and coronary heart disease (10%, 119 respondents).

Pain management (23%, 278 respondents) was also cited by a quarter of respondents, which was not surprising given the range of other issues raised and the complexity of health needs expressed.

Similarly, one in five (20%, 247 respondents) indicated that the people they care for have mental health issues, although again some of these are tested more specifically in the survey. It was interesting to note the high level of people being cared for with learning disabilities (17%, 203 respondents) and autism/Asperger's Spectrum Disorder (9%, 111 respondents), perhaps reflecting higher levels of diagnosis in recent years.

Whilst the overlap in categories should be remembered, the full range of responses below gives some sense of the variety of conditions requiring care, the type of care required, and impact on carers as a result. For example, where people are caring for relatives or friends with a physical impairment, they are more likely to have back pain from lifting and handling or bending. 3% of respondents (46) did not provide a response to this question.

Figure 8 Main health issues for cared for person – NLC area



Whilst just a small sample of carers were included in the qualitative research, participants cared for people with quite a variety of different health conditions, such as COPD, diabetes, cancer, Asperger's/autism, ADHD, epilepsy, learning disabilities, dementia and other conditions which had a significant impact on the individual and their need for care to be provided.

In the survey, there was little variation in issue by gender of carer, but older carers (75+) were more likely to be caring for someone who was frail elderly and had Alzheimer's/ dementia, most likely their partner or spouse. Younger carers were more likely to be dealing with pain management, mental health issues, learning disabilities and autism/Asperger's Spectrum Disorder.

Those caring for a parent/grandparent or spouse/partner/sibling were more likely to be caring for someone with age-related conditions, as might be expected, but those caring for a spouse/partner/sibling were also caring for more people with mental health issues, as were those caring for a child/grandchild. Those caring for a child/grandchild were also more likely to be caring for someone with learning disabilities, autism/Asperger's Spectrum Disorder and epilepsy.

The table below illustrates the distribution of stated health issues for those being cared for by the carers responding to the survey. As with all responses, this is not likely to be an exhaustive list of health issues, but the main ones the carer was willing to share via the survey. Again, those highlighted in red in the table below are at least 5% above the North Lanarkshire average and in green are at least 5% below the North Lanarkshire average. Frail elderly were higher in other areas (although the base is lower there so just a few people have made that difference). Mental health issues and learning disabilities were slightly more prevalent in Motherwell than in other parts of North Lanarkshire, for example.

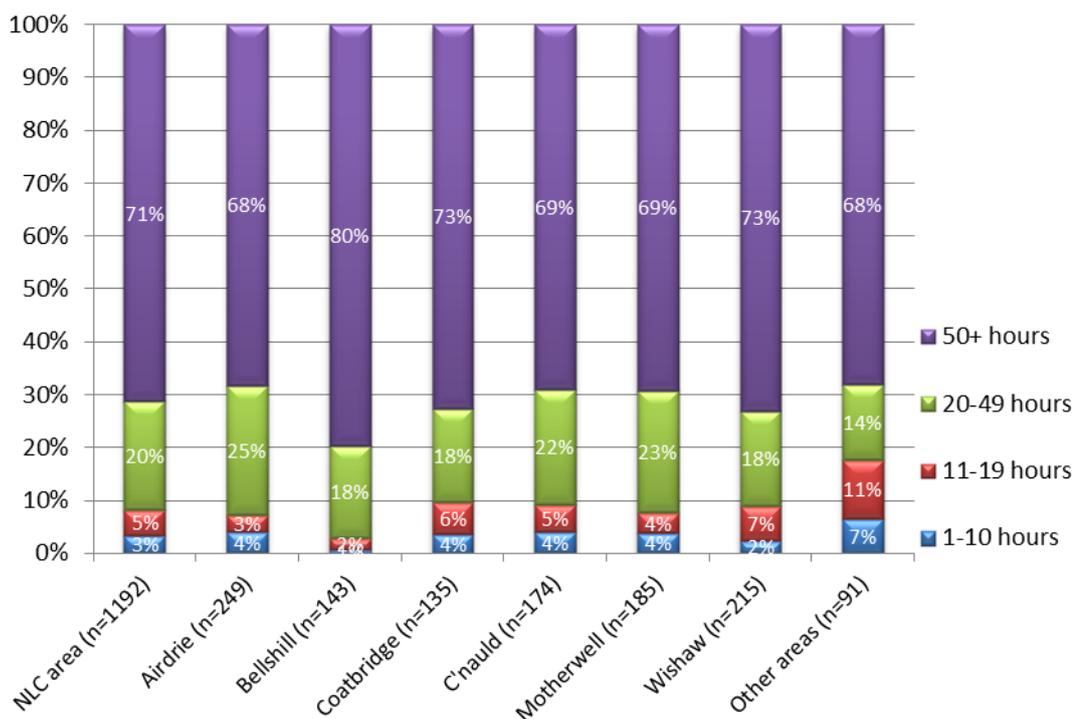
Table 1 Main health issues for cared for person – local areas

	NLC area (n=1221)	Airdrie (n=261)	Bellshill (n=153)	Coatbridge (n=140)	C'nauld (n=176)	Motherwell (n=188)	Wishaw (n=215)	Other areas (n=88)
Physical Disabilities	39%	41%	36%	44%	42%	32%	39%	44%
Frail Elderly	26%	30%	20%	24%	26%	22%	24%	39%
Alzheimer / Dementia	24%	26%	20%	22%	28%	24%	25%	22%
Arthritis	23%	29%	22%	27%	18%	18%	21%	27%
Pain Management	23%	25%	21%	24%	24%	21%	22%	22%
Mental Health Issues	20%	20%	18%	14%	21%	27%	23%	14%
Learning Disabilities	17%	12%	18%	14%	18%	25%	16%	13%
Hearing impairment	14%	17%	10%	15%	15%	15%	13%	10%
Stroke	12%	14%	20%	12%	8%	12%	8%	10%
Visual Impairment	12%	10%	12%	9%	14%	16%	12%	8%
Coronary Heart Disease	10%	9%	14%	6%	6%	12%	11%	11%
Autism / Asperger's Spectrum Disorder	9%	6%	12%	7%	10%	14%	8%	8%
Neurological	9%	10%	7%	11%	14%	6%	5%	11%
Skin Complaints	8%	7%	7%	9%	10%	6%	9%	9%
Epilepsy	8%	6%	7%	6%	11%	8%	8%	9%

3.3.3 Time spent caring

The amount of time spent every week in a caring role was substantial. The majority of carers indicated that they spend 50 hours or more in their caring role (71%, 849 carers) – more than a full-time job - with 9 out of 10 caring for at least 20 hours a week (92%, 1,092 carers). Just 3% of the sample (41) spent 10 hours a week or less caring and 5% (59) spent 11 – 19 hours a week. Although all areas had a fairly similar profile of hours spent caring, Bellshill had the highest proportion of carers spending 50 hours or more in this role (80%, 114 carers). 6% of respondents (75) did not respond to this question.

Figure 9 Weekly hours doing caring role



The amount of time spent caring was greatest for older people: 85% of carers aged 75 plus cared for more than 50 hours per week and this was statistically significantly higher than those in younger age groups. In contrast, those aged 36 – 55 were statistically significantly more likely to care for 20 – 49 hours per week (26%, 122 respondents) than those aged 75+ (10%, 16 respondents). There was also one carer aged under 18, who also cared for more than 50 hours per week.

Those caring for a spouse, partner, sibling or a child were significantly more likely to spend at least 50+ hours caring (80%, 445 respondents, and 84%, 217 respondents, cared for 50+ hours respectively) compared to those caring for a parent or grandparent (44%, 118 respondents, spent 50+ hours caring) or other relative/friend (34%, 11 respondents).

Those caring for another relative or friend were significantly more likely to spend 1 – 10 hours per week caring (16%, 5 respondents) than those caring for a spouse/partner (2%, 13 respondents) or child/grandchild (1%, 3 respondents).

Over the three years of the survey, the proportion of those caring for 50+ hours per week decreased slightly from 74% (321 carers) in 2013/14, to 73% (288 carers) in 2014/15 and to 66% (240 carers) in 2015/16 (which was significantly less than 2013/14).

3.4 The impact of caring

All carers and professional stakeholders were quite clear of the significant impact that caring has on the health and wellbeing of carers. Regardless of the amount of time spent caring per week, participants were clear that caring can have an impact in all sorts of ways. For example:

- The ongoing and repetitive physical requirements can affect carers' backs and joints, in particular.
- Lack of sleep can have an impact physically and mentally (it has been used as a form of torture for a reason!). Our bodies repair themselves during sleep and deep

sleep has been identified to be vital for our brains to 'file' memories and process our day. A number of conditions have been attributed to poor sleep, such as a weakened immune system, and mental health problems such as anxiety and depression illustrate the interconnected nature of the health issues carers experience.

- Caring inevitably means less time for the carer to do what they want to do – to shop, see friends and family, exercise, do what they love doing or just to have some 'me time'. This is a particular issue for those with big time commitments, through extensive caring responsibilities, paid work and other family life.
- Significant caring requirements can mean that carers have to reduce or give up work. This can have a significant impact on income, which can be compounded if the cared for person also contributed to household income. The financial impacts of caring can be very difficult to deal with, not least because it relates to both income and spending (increased heating costs from being at home, aids and adaptations required to help care, increased costs of transport, new clothing required if losing/putting on weight, etc.)

All carers were considered to be affected to one degree or another and these issues reflect the points raised in the literature. That would be expected of those who effectively provide care 24/7, in terms of both physical and mental impacts, but it was also noted for those who spend less time in a caring role. Even if people spend a small amount of time each week actively in a caring role, participants felt they will still be worried about the person they care for, and they will have less time for themselves, particularly if they are in paid employment, in addition to other potential health issues.

It is also important to note that people who adopt a caring role for others may do so when they are not in good health, and/or their health may deteriorate over time. Their health issues may be related to their caring role or can be independent of it, yet there is often an assumption that carers are 'fit to care'. This is clearly not always the case, particularly when older people are caring for their partners as they may also be affected by age-related conditions. The health of carers often comes 'second place' for carers themselves, who prioritise the cared for, and for health professionals, as their focus is often only on the person being cared for, and carers do not make time to see health professionals for their own issues.

Professional stakeholders and other carers reinforced how important it is for carers to maintain their health and wellbeing for their own sake and in order to sustain their caring role (albeit that they did not necessarily put that into practice themselves, or had learned the hard way in the past). The fact that different times of year impact on carers and those they care for differently was also highlighted. For example, Christmas and New Year can be a particularly challenging time to secure respite, access support services, the weather is challenging, daylight is limited so people spend more time indoors and it can be a difficult time of year for anyone who has lost loved one and/or is isolated. It is a time when people reflect on the past year and it is a family-focussed time so it can highlight deficiencies, loss and changes in people's lives.

However, participants stressed that carers generally express little interest in themselves at all, deflecting any questions which are asked and focussing on the person they care for instead: "*That's safer.*" Participants reported that carers may mention they suffer from anxiety but downplay big health issues like stroke, heart attack, etc. The view emerged that the timing of questions around a carers' health and wellbeing can make all the difference – for some, they need to be sufficiently affected to realise that they cannot ignore health and wellbeing issues any longer and be asked in the right way to elicit a positive response.

The role of the GP in assisting carers was perceived to be crucial, and the difference in approach geographically was highlighted by those who had experience of both North and South Lanarkshire. North Lanarkshire was perceived to be particularly proactive in terms of raising the profile of carers' health needs and responding to these, which was viewed

positively. The professional stakeholders highlighted their experience as carers, where their needs had not always been responded to positively. They were clear that if they had not worked in the roles they do, and were relying on information and access to services via the health and care providers they encountered in their caring role, they were clear that the support they would have known about and/or accessed would have been significantly restricted. Whilst the NLCT team aims to work with all 64 GP practices in North Lanarkshire, some practices work more effectively for and prioritise carers more than others. The NLCT team estimated that the vast majority – around 50 out of 64 - were working well.

3.5 Main health issues for carers

3.5.1 Overall survey results

The survey asked carers to indicate the main health issues they were experiencing from a tick-list. Anxiety and stress emerged as the most common health issue identified by carers who responded, with three-quarters (75%, 899 respondents) affected by this. Half (49%, 586 respondents) also cited depression/feeling sad and 30% (363 respondents) noted their isolation and feeling alone. The physical impacts of caring were also well-represented, with 44% (531 respondents) citing lack of sleep and 36% (434 respondents) experiencing back pain. The financial impact of caring also had an impact on carers' health (27%, 319 respondents).

The full range of responses is illustrated in the figure below. Several of the issues can be seen to be inter-related, for example mental health issues are listed but so are specific mental health issues such as anxiety and stress, and pain management is listed as well as back pain specifically. Please note that 5% of respondents did not share their health issues.

Figure 10 Main health issues for carers – NLC area



n=1,179

3.5.2 Changes over time

Over time, the profile of health issues has changed slightly, although several issues remain consistent for around the same proportion of carers. Anxiety and stress was consistently the most common health issue amongst carers who gave a response, with around three-quarters of carers citing this as a concern each year. Anxiety and stress was more likely to be cited by:

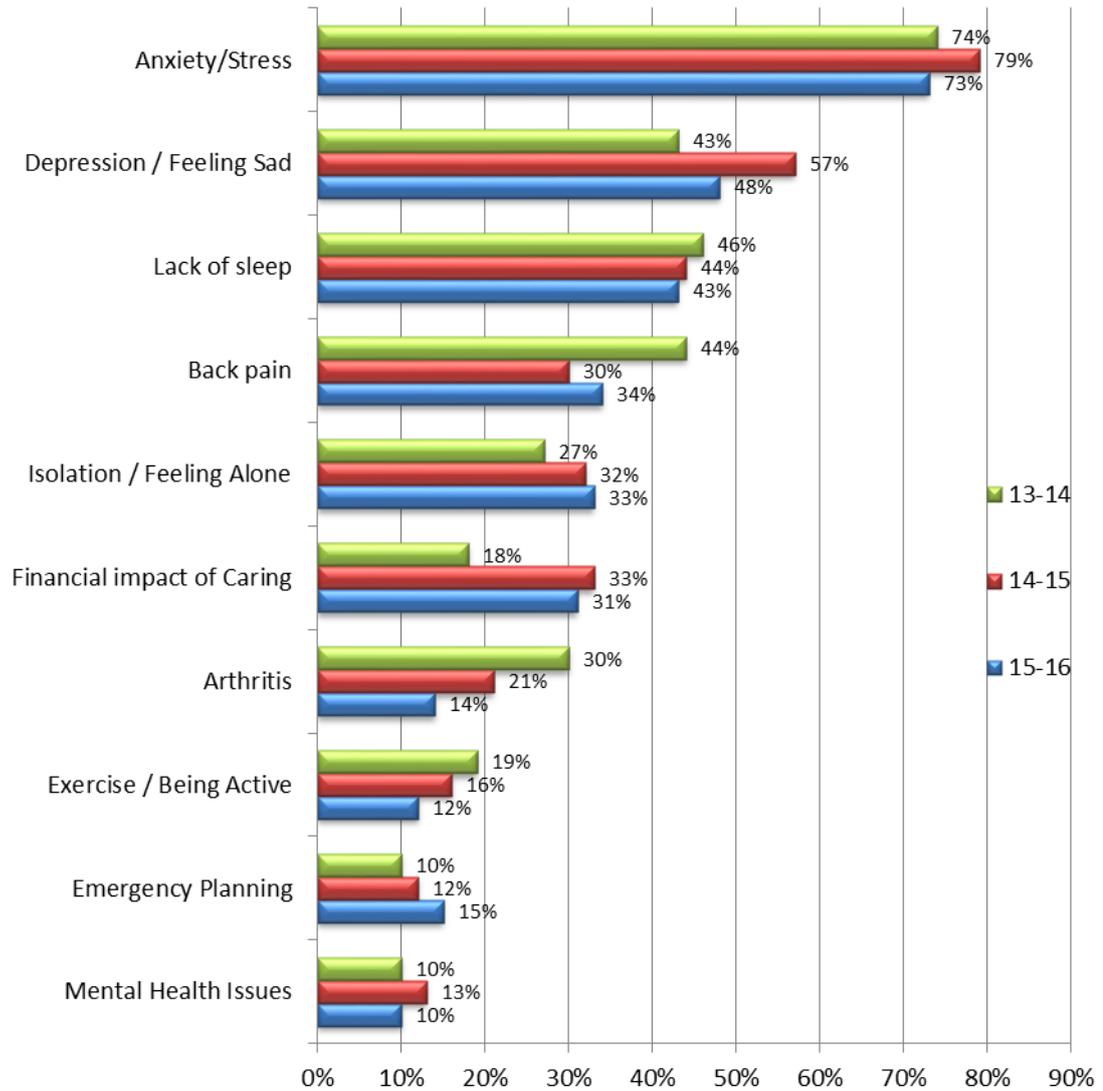
- those caring for 20 hours per week or more (28%, 291 carers) than for those caring for a shorter time (16%, 15 carers); and
- those caring for a spouse, partner or sibling than by those caring for a parent/grandparent or child/grandchild.

The following changes over time are noted:

-
- The **financial impact of caring** can be extremely challenging for some carers and it has increased significantly over time, suggesting it is becoming an issue for more carers (from 18%, 83 respondents, in 2013/14 to 33%, 123 respondents, in 2014/15 and 31%, 113 respondents, in 2015/16).
 - In contrast, **arthritis** wasn't represented as highly in later years of the survey as in the first year (30%, 136 respondents, in 2013/14, reducing to 21%, 79 respondents, in 2014/15 and 14%, 53 respondents, in 2015/16).
 - **Back pain** was also significantly less prevalent in later years (44%, 200 respondents, in 2013/14, reducing to 30%, 110 respondents, in 2014/15 and 34%, 124 respondents, in 2014/15). This may just reflect the different needs of the particular carers who responded to the survey, but could also reflect greater awareness and availability of access to lifting and handling training for carers.
 - **Depression/feeling sad** was significantly higher in 2014/15 (57%, 211 respondents) than in 2013/14 (43%, 197 respondents).
 - The challenge of **exercise/being active** was also significantly more of an issue in 2013/14 (19%, 88 respondents) than in 2015/16 (12%, 43 respondents).

The figure below illustrates the main health issues carers identified over the three years of the survey.

Figure 11 Main health issues for carers – trends over time



3.5.3 Ranking of health issues by area over time

The table below shows the ‘ranking’ of top five most mentioned health issues for carers from year to year, for North Lanarkshire as a whole and for each of the geographic areas. This shows that anxiety/stress was very consistently an issue for the largest number of carers in each year and in each area. Whilst the placings did vary slightly year to year and area by area, they were relatively consistent and the first three categories (left to right) were always in the top five (apart from lack of sleep in Bellshill in 2014/15).

Table 2 Top five ranked health issues for carers over time by area

		Anxiety/ Stress	Depression / Feeling Sad	Lack of sleep	Back pain	Isolation / Feeling Alone	Financial impact of Caring	Arthritis	Emergency Planning
NLC area	13-14	1	4	2	3			5	
	14-15	1	2	3		5	4		
	15-16	1	2	3	4	5			
Airdrie	13-14	1	4	2	3	5			
	14-15	1	2	4	4		3		
	15-16	1	2	3		5	4		
Bellshill	13-14	1	2	3	4			5	
	14-15	1	2	3		5	4		
	15-16	1	2		4	3			5
Coatbridge	13-14	1	4	2	3			5	
	14-15	1	2	3	4	5			
	15-16	1	4	2	3		5		
Cumbernauld	13-14	1	3	3	2			5	
	14-15	1	2	2	4	5			
	15-16	1	2	3	4		5		
Motherwell	13-14	1	2	3	4			5	
	14-15	1	2	3		4	5		
	15-16	1	2	3	5		4		
Wishaw	13-14	1	3	4	2			5	
	14-15	1	2	3		5	4		
	15-16	1	3	2	5	4	5		
Other areas	13-14	1	3	1	4			4	4
	14-15	2	1	3		4	5		
	15-16	1	2	2		4	5		

The table below shows the results for the total sample in each area and the fact that these do not vary hugely across the patch. The biggest difference was 10% more people in Coatbridge (46%, 62 respondents) citing back pain compared to the 36% (434 respondents) mean in North Lanarkshire. Those highlighted in red in the table below are at least 5% above the North Lanarkshire average and in green are at least 5% below the North Lanarkshire average. It must be noted that whilst the overall sample was substantial, the sub-samples for each area are smaller, so just a few people can make a big difference to the percentages and there were no statistically significant differences by area.

Table 3 Main health issues for carers – local areas

	NLC area (n=1197)	Airdrie (n=254)	Bellshill (n=143)	Coatbridge (n=136)	C'nauld (n=170)	Motherwell (n=199)	Wishaw (n=210)	Other areas (n=85)
Anxiety/Stress	75%	76%	80%	70%	75%	73%	79%	67%
Depression / Feeling Sad	49%	44%	53%	44%	50%	50%	51%	56%
Lack of sleep	44%	43%	41%	48%	49%	43%	43%	48%
Back pain	36%	36%	33%	46%	41%	32%	37%	26%
Isolation / Feeling Alone	30%	34%	30%	28%	29%	27%	30%	33%
Financial impact of Caring	27%	32%	24%	26%	25%	23%	27%	28%
Arthritis	22%	23%	18%	24%	24%	23%	22%	21%
Exercise / Being Active	16%	14%	17%	15%	19%	17%	13%	19%
Emergency Planning	12%	15%	16%	9%	13%	11%	8%	14%
Mental Health Issues	11%	14%	12%	8%	6%	11%	12%	9%
Pain Management	9%	10%	7%	12%	9%	11%	8%	9%
Physical Disabilities	9%	10%	11%	5%	10%	10%	6%	7%
Sexual Health / Relationships	9%	11%	8%	5%	6%	8%	11%	7%
Peer Pressure / Friendships	7%	10%	8%	2%	6%	8%	6%	7%
Hearing Impairment / Visual Impairment	7%	6%	6%	3%	8%	11%	5%	9%
Coronary Heart Disease	6%	6%	10%	3%	6%	8%	4%	8%
Smoking	6%	5%	6%	2%	8%	7%	9%	4%
Eating Disorders	5%	4%	6%	7%	8%	3%	3%	5%

3.5.4 Differences by age

As might be expected, older carers were more likely to experience physical health issues than younger carers, but younger carers were more likely to cite mental health issues. For example:

- Older carers were significantly more likely to cite **arthritis** (29%, 189 respondents aged 56+), compared to 13% (70) of those aged 55 or under.
- Older carers were significantly more likely to cite **hearing or visual impairments** (10%, 62 respondents aged 56+) compared to 3% (15) of younger respondents.
- Older carers were more likely to cite **coronary heart disease** (8%, 52 respondents aged 56+, compared to 4%, 21 younger respondents).
- Younger/middle-aged respondents were significantly more likely to cite **anxiety/stress** (81%, 424 respondents, aged 55 or under) compared to 72% (462 respondents) of those aged 56+.
- Younger/middle-aged people were also significantly more likely to cite **depression/feeling sad** (68%, 32 respondents, aged 26 – 35 in particular; but 57%, 301 respondents, aged 55 and under, compared to 43%, 276 aged 56+).
- Younger carers were also significantly more likely to cite **isolation/feeling alone** (34%, 178 respondents aged 55 and under) than older carers (28%, 180 respondents aged 56+).
- **Mental health issues** were also more likely to be cited by 55 and unders (15%, 80 respondents), in contrast to just 7% (47) of those aged 56+. The one carer aged under 18 also cited mental health issues as their sole health issue.

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- **Exercise and being active** was a particular issue for younger respondents (42%, 8 aged 18 – 25, and 36%, 17 aged 26 – 35), but the low base should be noted here. It was significantly higher for those aged 55 and under (20%, 104 respondents) compared to those aged 56+ (12%, 80 respondents).
 - **Lack of sleep** was also significantly higher for those aged 55 and under (50%, 261 respondents) than for those aged 56+ (40%, 261 respondents).
 - **Smoking and eating disorders** were not particularly big issues for carers but carers aged 55 or under were significantly more likely to cite these (9%, 46 respondents, and 7% 37 respondents respectively) than those aged 56+ (4%, 25 respondents, and 3%, 22 respondents respectively).
 - The **financial impact of caring** was significantly higher for 55 and unders (35%, 184 respondents) than for those aged 56+ (21%, 135 respondents).

3.5.5 Differences by time spent caring

The longer carers spent caring each week, the more likely they were to experience the following health issues:

- **Anxiety and stress:** 76%, 173 respondents, 20 – 49 hours and 78%, 627 respondents, 50+ hours in comparison to 56%, 51 respondents for those caring for less than 20 hours.
- **Depression:** 51%, 411 respondents, caring for 50+ hours in comparison to 33%, 12 respondents caring for 1 – 10 hours.
- **Lack of sleep:** 47%, 379 respondents, caring for 50+ hours and 41%, 94 respondents, caring for 20 – 49 hours in comparison to 27%, 15 respondents, caring for 11 – 19 hours and 31%, 11 respondents, caring for 1 – 10 hours.
- **Isolation and feeling alone:** 33%, 269 respondents, for those caring for 50+ hours but 19-23% for each of the other categories.
- **Financial impact of caring:** 28%, 291 respondents, caring for 20+ hours per week, compared to 16% (11 respondents) of those caring for less time.
- **Mental health issues:** 11%, 116 respondents, of those caring for 20+ hours per week, in comparison to 7%, 6 respondents, of those caring for less time each week.

3.5.6 Differences by who carers care for

When looking at carers' stated health issues alongside who they care for, the data shows the following statistical differences:

- Those caring for a spouse, partner or sibling were significantly more likely to cite **back pain** (41%, 228 respondents) compared to those looking after a child/grandchild (32%, 84 respondents).
- Those caring for a spouse, partner or sibling were significantly more likely to cite **arthritis** (28%, 155 respondents) compared to either those caring for a parent/grandparent (18%, 48 respondents) or a child/grandchild (17%, 46 respondents).
- Those caring for a spouse, partner or sibling were significantly more likely to cite a **hearing or visual impairment** (10%, 53 respondents) than those caring for a parent/grandparent (3%, 7 respondents).

- Those caring for a spouse, partner or sibling were significantly more likely to cite **coronary heart disease** (9%, 51 respondents) than either those looking after a parent/grandparent (3%, 9 respondents) or a child/grandchild (4%, 10 respondents).
- Those caring for a parent/grandparent (13%, 36 respondents) or child/grandchild (16%, 42 respondents) were significantly more likely to cite **mental health issues**, compared to those caring for a spouse, partner or sibling (7%, 39 respondents).
- Those caring for a parent were significantly more likely to cite an **eating disorder** (8%, 22 respondents) than those caring for a partner (3%, 16 respondents).
- Those caring for a child/grandchild were significantly more likely to be experiencing **anxiety/stress** (82%, 217 respondents) compared to those caring for a spouse, partner or sibling (72%, 397 respondents).
- Those caring for a child/grandchild were significantly more likely to cite **sexual health and relationship issues** (12%, 33 respondents) compared to those caring for a spouse, partner or sibling (6%, 34 respondents).
- Those caring for a child/grandchild were also significantly more likely to cite **bullying** (7%, 18 respondents) than those caring for a spouse, partner or sibling (2%, 13 respondents).
- Those caring for a child/grandchild were significantly more likely to cite **learning disabilities** (4%, 11 respondents) than those caring for a parent/grandparent (1%, 2 respondents).

3.5.7 Inter-section of health and wellbeing issues for carers and cared for person

The data also highlights that carers who are caring for people with specific conditions were, in turn, significantly more likely to be dealing with health issues of their own, as follows:

- Those caring for people with **physical disabilities** were significantly more likely to be experiencing lack of sleep (48%, 224 respondents), back pain (47%, 218 respondents), arthritis (28%, 131 respondents), challenges of exercise/being active (21%, 95 respondents), physical disabilities themselves (14%, 63 respondents), sexual health/relationship issues (11%, 51 respondents) and eating disorders (7%, 31 respondents).
- Those caring for **frail elderly** were significantly more likely to be experiencing lack of sleep (51%, 153 respondents), isolation/feeling alone (35%, 104 respondents), the financial impact of caring (32%, 95 respondents), arthritis (28%, 82 respondents), challenges of exercise/being active (20%, 61 respondents) and physical disabilities themselves (13%, 38 respondents).
- Those caring for people with **Alzheimer's/dementia** were significantly more likely to be experiencing anxiety/stress (81%, 230 respondents), depression/feeling sad (57%, 161 respondents), lack of sleep (50%, 142 respondents), isolation/feeling alone (37%, 104 respondents), arthritis (28%, 80 respondents) and pain management (13%, 38 respondents).
- Those caring for people with **arthritis** were significantly more likely to be experiencing back pain (52%, 140 respondents), arthritis themselves (39%, 104 respondents), the challenges of exercise/being active (21%, 55 respondents), pain management (16%, 43 respondents), physical disabilities (13%, 36 respondents), hearing or visual impairment (11%, 30 respondents) and coronary heart disease (9%, 25 respondents).

- Those caring for people with **pain management issues** were significantly more likely to be experiencing lack of sleep (51%, 138 respondents), back pain (49%, 131 respondents), the financial impact of caring (35%, 93 respondents), arthritis (35%, 95 respondents), the challenges of exercise/being active (26%, 71 respondents), emergency planning (16%, 42 respondents), pain management themselves (20%, 54 respondents), physical disabilities (14%, 37 respondents), hearing or visual impairment (13%, 35 respondents) and coronary heart disease (10%, 26 respondents).
- Those caring for people with **mental health issues** were significantly more likely to be experiencing anxiety/stress (83%, 198 respondents), isolation/feeling alone (37%, 89 respondents), the financial impact of caring (35%, 84 respondents), the challenges of exercise/being active (20%, 48 respondents), mental health issues themselves (24%, 57 respondents), physical disabilities (12%, 29 respondents), sexual health/relationship issues (14%, 33 respondents), peer pressure/friendship issues (14%, 33 respondents), eating disorders (8%, 18 respondents) and bullying (8%, 18 respondents).
- Those caring for people with **learning disabilities** were significantly more likely to be experiencing anxiety/stress (81%, 159 respondents), lack of sleep (58%, 113 respondents), back pain (45%, 89 respondents), the challenges of exercise/being active (25%, 49 respondents), pain management (13%, 26 respondents), sexual health/relationship issues (16%, 32 respondents), peer pressure/friendship issues (14%, 27 respondents), smoking (9%, 18 respondents), bullying (7%, 14 respondents) and learning disabilities themselves (5%, 10 respondents).
- Those caring for people with **autism/Asperger's Spectrum Disorder** were significantly more likely to be experiencing anxiety/stress (83%, 91 respondents), depression/feeling sad (60%, 65 respondents), lack of sleep (59%, 64 respondents), the financial impact of caring (36%, 39 respondents), the challenges of exercise/being active (27%, 29 respondents), sexual health/relationship issues (17%, 18 respondents) and peer pressure/friendship issues (12%, 13 respondents). However, they were also statistically less likely to have arthritis (15%, 16 respondents), reflecting the younger profile of these carers.
- Those caring for people with **epilepsy** were significantly more likely to be experiencing back pain (51%, 47 respondents), the financial impact of caring (38%, 35 respondents), arthritis (34%, 32 respondents), emergency planning (19%, 18 respondents), mental health issues (24%, 22 respondents), peer pressure/friendship issues (17%, 16 respondents), hearing or visual impairment (12%, 11 respondents) and eating disorders (13%, 12 respondents).

3.5.8 Qualitative feedback on health issues

Despite carers having a reputation for reticence over addressing their own health needs, the focus on carers' health issues was made clear by both NLCT and the FMR researcher prior to the discussion and carers were forthcoming about the health issues they had experienced, albeit sometimes with a tendency to initially talk more generically of carers' health and wellbeing issues rather than their own. Once the discussion turned to personal experience, the issues they had faced were discussed initially on an unprompted basis and any which had not been raised were then tested with carers.

A number of issues emerged quickly from the discussions. For example, **anxiety, stress and the feeling of isolation** which carers experience were some of the first issues to be highlighted.

"It's very difficult when you get the diagnosis (for Autism Spectrum Disorder or ASD). You're grieving for the child you thought you had."

Several carers were taking medication for anxiety and depression. However, participants were quick to highlight the role NLCT and services they had been signposted to by NLCT had in helping them to address their health issues:

“I know that other people feel the same now and I can drop in [to NLCT] and talk about things. It’s good to know you’re not alone. I’m going to groups too and have spoken to people. It helps not to have all that burden yourself, and people have suggested help that I didn’t know about.”

Volunteering had also helped another carer:

“They’re very supportive [other volunteers] and help me so much. It’s changed my life.”

Challenges in **eating and drinking well** were also highlighted by carers. One man caring for his wife reported that his waist had dropped from 38” to 30” (through a combination of stress, not eating well and illness). Others reported comfort eating or not eating as healthily as they would have liked because they didn’t have time to cook or ate too late in the evening because of their caring responsibilities.

“I go straight to [cared for person’s house] from work, sort everything out there and don’t get home until about 9 o’clock. It’s too late to eat properly.”

Alcohol consumption was also an issue:

“It’s easy to get into bad habits and just have a drink after you’ve finished all your jobs. I was drinking every night.”

...as was **smoking**:

“I know it’s bad for me, but it’s hard to quit when you’re so stressed. I have cut back, though.”

Some highlighted services which had helped relieve them of some stress, such as the cared for person having an alarm to alert the service provider if they need assistance.

“That’s better peace of mind for £5 a week – that’s worth it.”

When **prompted**, other issues emerged for people. For example, poor sleep was perhaps something that carers just “*have to deal with*”, so it had not immediately sprung to mind when thinking about health and wellbeing.

“Sleep is always an issue. My son has disturbed sleep. NLCT helped me to access Caring for Carers Lottery funding and I went to college for twelve weeks to have holistic therapies. I don’t drive so it was a big help that they sorted out transport for me. That took a lot of stress out of going. It was great – I made new friends and we keep in contact.”

“I was getting frequent UTIs and was really run down. I was tired and crabbit from the lack of sleep. You’re always listening for them [cared for person].”

Related to lack of sleep, **exhaustion** was also clearly apparent for most of the carers who gave their views. Carers were exhausted by the extra workload which caring entails, and the physical and mental impacts which contribute to that feeling of exhaustion and ‘burn out’.

The **impact on relationships and social networks** was also articulated by carers. This has different aspects. For example, marital relationships had broken down because of the impact of caring for a child with additional needs or the dynamic had changed from that of a

husband and wife to carer/cared for when one partner became ill, which they found difficult to cope with and accept.

“Yvonne was very good about mediation, to help me to deal with it [marital breakdown] effectively. We’re as amicable as we’re going to be now and we can negotiate who’s doing what.”

Caring also has an impact on carers’ relationships with other family members. For example, if one child has additional needs and consequently is perceived to receive more attention or to not have to abide by the same rules, this can affect the dynamics with other children in the family and cause problems.

Friendships were also seen to be affected, with carers reporting that existing friends often did not really understand their circumstances as a carer and how this affected what they were able to do, in addition to affecting their priorities and perspectives on life. For some at least, the new friends they had made amongst carers’ groups and activities were now the ones they favoured as there was a greater degree of understanding – they don’t have to explain themselves if they’re feeling low or can’t make something at the last minute, and they feel supported.

“[of existing friendship group] The kids are so different we’ve sort of drifted apart. We’ve not got a lot in common with ‘mainstream’ friends any more. We mostly see people from the carers side now. They understand.”

Others had one or two close, supportive friends and this made a big difference to them as it allowed them, for example, to go on holiday knowing that the person they cared for would be looked after.

Being able to go on **holiday** had been an issue for some carers. One carer reported they had accessed a grant from Take a Break Scotland to enable them to go on holiday, which was very much appreciated, another had a trip to Blackpool, and another had a caravan break. However, the number of breaks or trips away carers have appeared to be much lower than others in the community, and arguably they are the people who need one most because of the impacts of their caring responsibilities.

Not taking a break or more breaks came down to a number of factors: not having the money to do so and not having others who could perform the caring role in their absence were core to this, but carers also highlighted that the person they care for can make them feel very guilty for taking a break.

Time to **exercise** was an issue for some carers who gave their views, whilst others managed to fit in time to walk and/or go to the gym. This depended very much on working commitments and the health issues of the person they cared for.

The GP stakeholder reported, unprompted, the main issues presented by carers to be:

- poor sleep quality;
- inability to look after their own health and wellbeing properly because of lack of time which leads to stress, anxiety and depression if they feel isolated;
- arthritis in older carers, with joint pain;
- issues with their own health which are not caused by caring but can be exacerbated by the strain of caring, such as COPD or coronary heart disease;
- back pain; and
- not eating healthily.

Other professional stakeholders highlighted stress and anxiety as the most common health and wellbeing issues for carers, and depression as *“a lot are struggling”*. The fact that carers also often have long-term conditions themselves, especially older carers, was also highlighted. For example, it is not uncommon for people who may be considered to be older

people themselves to be caring for other older people, such as the example given of a 67 year old caring for their 92 year old mother.

The professional stakeholders also highlighted the fact that parents expect their children to look after them, but this means that some carers are “on their knees” with the combined pressures of paid work, looking after children, their own household and caring for parents and their household. The help which they may offer to a loved one automatically and without question in the short term can be very difficult to sustain in the longer term, yet it becomes expected. In addition, some parents refuse to have ‘outside’ help which makes the situation very difficult for the carer. The older person does not perhaps appreciate the impacts on their carer and professionals noted that cared for people can become quite selfish. There can be many conflicting feelings involved in caring for someone. Guilt is often present but it can have a devastating impact on individuals and their decision-making processes. It was interesting to note that carers who had previous experience of caring, learned from that if called upon to care for others at a later date by, for example, putting a boundary around what they did and ensuring other support was accessed too.

3.6 Managing health and wellbeing

Carers understood that investing some time in their own health and wellbeing was important, for themselves and so they could maintain their caring role effectively. For some, this was more of a theoretical understanding than something they regularly put into practice, however. Carers reported that having a busy life and also having caring responsibilities leaves little room for looking after oneself and some felt guilty doing so. For example, one carer highlighted that whilst SDS was very positive and meant that budgets could be tailored, this meant managing five members of staff, which also takes time, leaving less for the carer to focus on their own needs.

Caring commitments hindered carers from managing their own health and wellbeing needs in a range of different ways but all effectively boil down to not making enough time for themselves. These included making the time to attend appointments or seek support, to exercise, to shop and cook healthy meals, to ‘maintain’ themselves (get their hair or nails done or have a massage), meet friends or just have time to relax or do whatever makes them happy. All of these things impact on a person’s physical and mental health and wellbeing. The key thing to emerge from discussions was that carers can feel very guilty about taking time for themselves as there are always other things on their ‘to do’ list and they find it difficult to put their own needs ahead of the cared for person and other commitments.

Others had learned over the years – sometimes the hard way, as they had experienced health and wellbeing crises – that they needed to look after themselves too, often as there was no-one else to do that for them.

“I’ve learned that over the years from groups and from what happened to me. The kids need me more now. I need to look after myself or I’ll be no good to them. I’ve just finished a counselling course and I had to prove that I matter too, it’s not selfish to look after myself too.”

“I put things off but ended up having a panic attack and going into hospital. I was very stressed, with high blood pressure, palpitations and a fast heart rate. So much stress and anxiety but I couldn’t stay for tests as I had to get back [for caring role].”

One carer shared the fact that they now have an emergency plan in place so this gives them peace of mind, should they become unwell and not able to provide the level of care they currently do.

Health professionals reported that some carers were good at focussing on the health and wellbeing of the person they care for which came at their own expense, sometimes even if they had a health issue which required medical attention – some can refuse or put off

treatment because they feel they have to be there to perform their caring role. The demands of the caring role can make some carers focused on that alone. This varied from person to person and also how they were feeling. For some carers, the time had to be right to talk about themselves.

“They can sometimes try to not bother about themselves, and just want to talk about the person they care for.”

“Carers will often say they can’t be admitted to hospital because of their caring role. They put themselves on the back burner and will only go in if it is a significant issue they can’t ignore. But even then, some will try to put it off. They don’t see their own health needs, or see them as less important. They forget about themselves, often without realising it. Respite can be planned so they can attend appointments or go into hospital if required, but they don’t see that.”

3.7 Carers health needs check up

Several carers had been referred by NLCT or called by their GP surgery for a carer’s health needs check-up. Carers aged 40-64 are able to access the Keep Well health check service, an annual health check with the Practice Nurse at their GP surgery. Until recently, carers were also invited to attend a health check at their GP practice, as part of the enhanced service provided by GPs. The health check involves a physical check-up (which appeared to vary by carer/surgery, but this may also have been due to participant recall), including things like listening to their heart/lungs, blood pressure check, blood tests such as cholesterol and diabetes, height/weight to calculate BMI, plus a general discussion about medications taken and lifestyle issues (like healthy eating, exercise and alcohol consumption). This is also an opportunity for carers to raise any health concerns they have, as a result of their caring role or otherwise. Keep Well is then able to assist carers with improving their health via free access to services including weight management, gym passes, counselling and physiotherapy.

Whilst carers could not always remember how the health check had come about, those who had participated found it to be very useful and reassuring (particularly if they had been concerned about something). All felt it was important to provide this health check for carers as they generally do not prioritise their own health and this annual ‘MOT’ helped to remind them to do so. As a result, they would recommend it to other carers and some had already done so. The invitation to have the ‘flu vaccine was also appreciated by those who would not otherwise have received an invitation.

For one carer, this Keep Well health check had a particularly significant impact, as it led to the diagnosis of cancer, which has now been successfully treated. Another found a lump which was diagnosed as a hernia and they have had an operation to correct that. Others had also been referred on for further assistance with health issues, which was very much appreciated.

All carers appreciated that they were being looked after and were able to check out any health and wellbeing concerns they had. As with the role of the NLCT team, the value of a ‘listening ear’ should not be under-played, particularly as carers are often isolated and do not get the opportunity to talk of their own concerns, fears and issues. Referral on to assistance from Social Work or carers organisations if the needs are social rather than medical, was also mentioned by professional stakeholders as being helpful where appropriate.

3.8 Financial impacts of caring

Carers highlighted that caring has impacted on them financially, in different ways. All of the following issues were raised by carers on an unprompted basis, illustrating how ‘front of mind’ and significant they are, and the points were raised, and returned to, at different points

in the discussions. The **increased cost of living** because of the need to have **heating** on all day, the need to **adapt** their home to be able to care at home (for example mobile pieces of equipment to improve quality of life or more structural changes), having to pay for care or support (such as alarms or respite cover) and so on means that more money is going out of the household.

Less money is also coming into the household, however, where carers have had to **give up or reduce paid working hours** and not all carers were able to access **benefits** at all or fully, so any savings carers have may have to be used to support the cost of caring.

“I don’t get any carer’s allowance as [cared for person] has to claim that and he won’t admit he has a condition. He doesn’t get the benefits he should either.”

The precarious nature of benefits was also highlighted by a carer who spoke of the number and complexity of benefit forms, the need for assessment (for PIP) and the *“two strikes and you’re out”* rule regarding rescheduling appointments (they had received notification of a 9am appointment in Glasgow which was impossible for them to make). The challenge of receiving the correct level of benefit support was also highlighted, as carers need to know what they are entitled to (not always easy) and fight for it, as the correct amount is not always immediately forthcoming.

“It probably has. I’m forced to work part-time because my son won’t go to anyone and it’s hard to get childcare for children with additional needs because the staff quotas need to be different. So I reduced my hours as low as I can and make do.”

“I applied for SDS but was refused because of his age. There is so much that money could help with, it could help all of us. Things like one to one swimming lessons or horse therapy. It would be a day out for everyone.”

A lack of support, or slow response, from the public sector may also have an impact on carers who have to find a solution to care needs themselves as they feel they are *“in limbo”* otherwise.

“Social Work did a Carer Needs Assessment a while ago but nothing has come from it.”

3.9 Recognition and support of carers’ health

Discussions explore to what degree carers felt their health and wellbeing was considered and supported by health and care professionals, the Third Sector and their employers.

3.9.1 Health and care professionals

Whilst there was a recognition that some health and care professionals they encountered in their caring role (or otherwise) will inevitably be better at supporting carers than others, the feedback from carers was that there is plenty of room for improvement on this. Carers felt that there was much greater emphasis on the individual(s) they care for, even if they clearly had health and wellbeing issues too.

“No! They don’t ask how I am.”

“Even when I went to the GP they asked about [cared for person]. They hadn’t even considered I was there for me.”

“They think much more about him. I recently asked Social Work to re-evaluate our situation and they gave us a befriender – but it wasn’t for

me, it was for him [cared for person]. They sit with him for two hours every second Thursday but it's not long enough for me to do anything."

"If I hadn't known what to do and where to go for support through my working role, I would have been lost. No support was offered at all."

There were some positive comments too, however, which was reassuring to hear:

"The Practice Nurse is great."

"The Learning Disability Team are fabulous. They've given me good support since the diagnosis."

3.9.2 Carer support in the Third Sector

The research also sought to explore the support available to carers around their health and wellbeing in the Third Sector.

North Lanarkshire Carers Together

Whilst the carers were recruited via NLCT and it would be expected that they would be positively pre-disposed to the organisation, the strength of feeling was notable. Carers were very quick to comment on the different positive aspects of NLCT (and its purpose as an organisation), the staff and the support they had received. Comments were made prior to the discussions properly starting, throughout the discussion and once the agenda had finished – there was no need to prompt carers for feedback on NLCT!

The overarching sense was that carers felt NLCT was there to support them whenever they needed them and this had, and continues to have, a very positive impact on their health and wellbeing.

"Knowing someone understands and is there to support you makes all the difference."

"Here [NLCT] saved me."

"They were amazing. I didn't want to be here. I wanted to die. I couldn't handle it [caring]. But I've broken through now. I can go on holiday, I'm happy now."

"I know they've got my back."

A number of aspects of support were identified by carers including the fact that NLCT had identified that they were a carer (as they were previously unaware of this), the team had provided useful information and referred/signposted to useful services, supports, activities and courses, and linked carers to other carers for peer support.

"I didn't know I was a carer until NLCT identified me. One day I went to the GP and Yvonne was there and I spoke to her. As we were chatting I realised I was a hidden carer, I'd never thought about it before. I thought I was just a mum... but I was struggling."

"I got involved with NLCT. They signposted me to things and gave me a pack, which had a lot of information in it. The GP takes carers on board and we all get an annual health check and a flu jab, which is great. The newsletter told me about a few courses happening with other agencies at NLCT. Introduction to Autism was the first one and it was fantastic! Very useful. The newsletters give other information like where to go for support, peer support. I found out what I could apply for and what I could access for me as a carer and for my son. I've been to the coffee mornings and it's a good social group. You have a coffee and a blether

and I've found out things I didn't know, like the cinema card I can apply for. NLCT can signpost me to whatever I need advice on."

"The girls here [NLCT] are great. Having somebody to talk to makes a big difference and to give me information that helps me. It helps other people too as I pass it on to other people who might benefit from it. I feel better if I help others."

"It's lovely to be able to pop in here [NLCT] if I'm out and talk to people who understand. They're all so wonderful – Donna when you first come in the door, Yvonne, Corinne, everyone. They can't do enough for you and that helps more than I can say, just knowing that they are there if I need them."

"I felt welcome."

"I got a stair lift, which made such a difference!"

"They're here for me. My wife was discharged from hospital and I expected carers to come and help, but no-one did. I called Yvonne and she sorted it out for me. Monklands just send people home without any support."

One less obvious aspect of NLCT's offering which was rated highly, was the fact that carers could drop in to the office when they were nearby.

"NLCT staff are like a wee directory. They respond to your pleas for help and you can just have a coffee and a blether."

"I'm a big fan [of NLCT]. They help and they understand, even when they're busy."

"I didn't know where to look but NLCT make it easy. They said 'Let us be your legs' and found out what I needed."

Several carers highlighted that they also attend the NLCT AGM/conference and enjoyed these. They reported that they enjoyed meeting other carers and hearing and/or thinking about things they weren't always aware of. The fact that transport and lunch was provided was also really appreciated by carers, as it was one less thing to have to think about

"There are no stumbling blocks, they think of everything."

The perceived lack of other support for carers was also highlighted:

"There is no help. The only help I've had has been from Carers Together."

Non-NLCT based professional stakeholders actively encourage carers to contact NLCT because they rated the team and services provided highly. The initial contact where needs were identified and then the carer is referred/signposted on was perceived to be very important. They also refer carers to other carers' organisations and condition-specific support organisations.

Other organisations/groups

A few other Third Sector organisations or groups were mentioned by carers, but most primarily had contact with NLCT.

"Little Stars and the groups I go to are great. I was told about it when we got the diagnosis [autism]. They have a kids group and a parent support group, which has been a massive support. I class them as friends now."

Lanarkshire Carers Centre and One Parent Families Scotland were also rated highly. The Third Sector organisations carers had come into contact with were all seen to work well together, which facilitated sign-posting.

“I go to One Parent Families Scotland now and have accessed legal advice, for example. OPFS links up with NLCT too. I go to Lanarkshire Carers Services too. I’ve got a carers card and access their holistic therapies.”

3.9.3 Working environment

Some carers who participated in the research worked – full-time or part-time - whilst others did not. The majority reported flexible work practices, for example around hours worked and time off when required, but it must be remembered that those experiences are with current employers which enable working alongside the caring role – this is not necessarily representative of the wider working environment or of previous employment. For example, carers said they had to take annual leave to attend medical appointments for the person they cared for in previous jobs.

“Work is very good. They have a flexible policy for working parents. If I worked more hours I could take unpaid leave in the summer, but I have set hours and know what overtime I can do at Christmas because of my carers’ allowance. They understand I’m on my own so I can’t be flexible. They’re very flexible. They give you ‘me time’ for emergencies so, for example, if the person you care for is in hospital it’s not classed as an absence, it’s unpaid leave. They’re all great. I’m quite lucky but I know others find it difficult to get to meetings and things. Employers need to put themselves in our shoes and show some respect for what carers are doing, especially if they have a full-time job too.”

Existing bosses and working policies were generally perceived to be supportive but this was not always reinforced by colleagues in practice, however. For example, carers reported different experiences depending on what was wrong with the person they were caring for – some conditions seemed to elicit more compassion and understanding than others – and colleagues’ patience wearing thin if emergencies happened regularly (which is obviously completely outwith the control of the carer). This is an important point to consider as, for many carers work is actually akin to respite as they can focus on something else and be themselves. If the working environment is not sympathetic to the carer’s position, it is no longer a ‘safe space’ but can exacerbate stress and anxiety, make carers ill and cause them to take time off. This is something of a vicious circle, so work is needed to address the stigma of caring and level the playing field as there should not be perceived greater value in caring for one condition over another and everyone’s experience of caring is different.

“No-one ever says ‘are you ok?’ I’ve had no real support.”

Carers reinforced the importance of work, not just as a source of income but as space to be themselves and not “just be a carer”. However, carers can feel left out because of their caring role, as this restricts them from participating in social activities outside work time.

“People don’t ask me, or don’t usually ask me now, because they know what I’ve got to do. I do feel left out.”

Interestingly, carers highlighted that they felt much more loyal to employers who gave them flexibility to accommodate their caring role. They felt they were more likely to stay in that role and to give more to the job, as a result.

3.10 Learning from experience

Carers were asked what, if any, support they had found particularly useful in their caring role. The work NLCT has taken forward with GP surgeries in North Lanarkshire was appreciated by carers, both in terms of the profile and priority awarded to carers because of the carers' database, priority access for carers and awareness raising work but also because of the annual health checks. The role of the practice nurse was seen to be a critical one for carers, as they know and understand the issues carers are facing, they get on well with them and feel able to raise concerns.

"I like the fact the GP knows I have [cared for person], and I'm on the carers' database. I feel the GP is more considerate towards me and interested in me, which helps me more."

"Being able to access the amount of support that I have. Speaking to people and having their support, and I'm more happy because I support them too. We're not alone any more. Isolation and loneliness is massive for carers and it impacts on your health. Knowing people are there for me and it's up to me to take up that support helps. I don't know where I would be if I didn't have the support I have!"

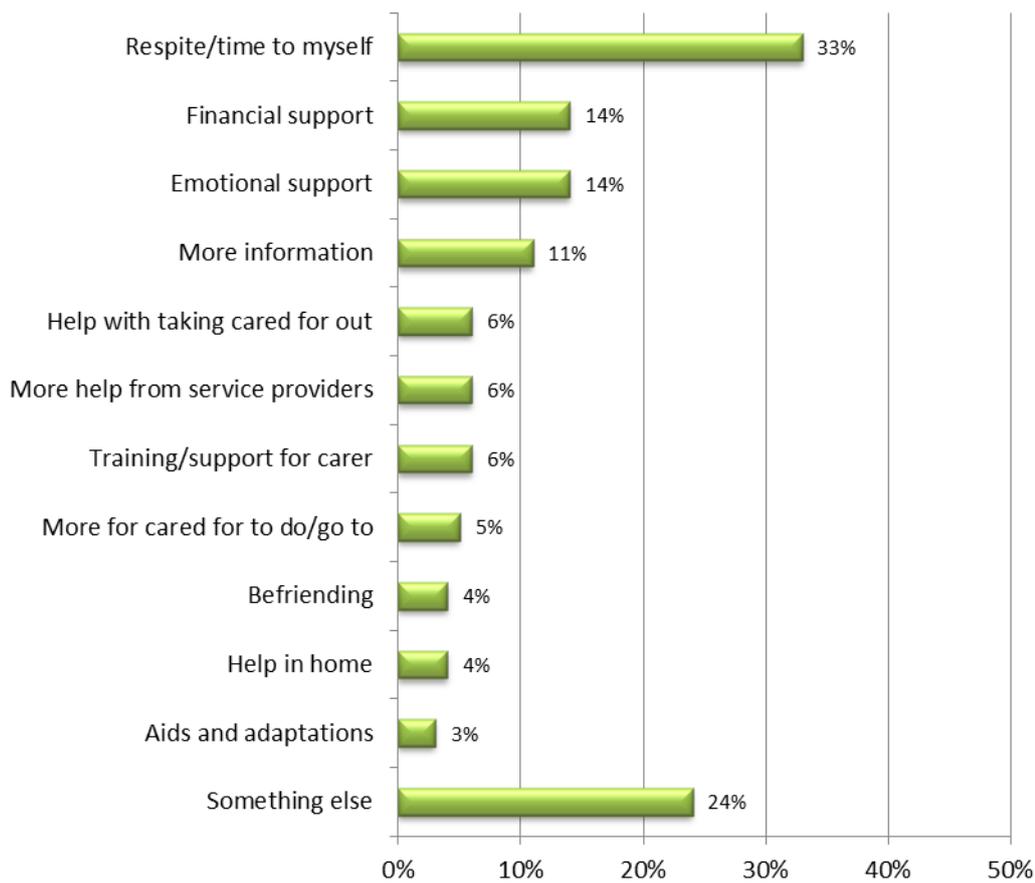
The role of technology was highlighted as being useful when caring for people with dementia, for example. This may not suit everyone, but it can alleviate concerns and give peace of mind, particularly around remembering when/what medication to take, alarms, tracker/locators, etc., when caring for people with dementia. This can therefore benefit both carer and cared for.

3.11 Suggestions for the future

3.11.1 Additional support needs of carers

The survey sought to gain insight into any additional support needs carers may have. Of those who gave a view (78%, 988 respondents did not), respite came through most strongly, with a third (33%, 91 respondents), followed by financial support (14%, 40 respondents), emotional support (14%, 39 respondents) and more information (11%, 32 respondents). A number of very specific responses were given to this question, so they were grouped into themes as far as possible (which accounts for the significant number of other responses as many were only mentioned by a small number of people), but the full range of responses is included in the data tables.

Figure 12 Additional support needs (grouped) – NLC area



n=279

3.11.2 What could/should carers do themselves?

All participants were asked what they could or should do themselves to support their health and wellbeing. The key response was around making sure carers took time out for themselves, even if only a short amount of time, and recognising their own worth. The importance of sleep, exercise, healthy eating and keeping on top of your own health checks were also prioritised by professional stakeholders.

“It’s all about the mindset – I’ve had to learn to put myself first sometimes. You need to realise your worth. What would the government be paying if you didn’t do it? It’s a valuable and good job, I learned that with counselling. You can’t burn yourself out.”

“We need to look after ourselves better, even if it’s only making five minutes. It’s very difficult because we are so busy and it’s easy to just put things off.”

“We need to be a bit more selfish. It’s no good just putting the person we care for first, we’ll be no good to them if we’re unwell so it’s not really being selfish at all.”

“Try to get exercise, eat healthily, comply with medical/health checks, get as much sleep as possible, take help when it is offered and ask for help when you need it.”

“Take time for themselves, even if it is only ten minutes to read a magazine.”

However, for some carers, it still came back to the priority being on the cared for person:

“At the end of the day, if [cared for person] is happy, I’m happy.”

3.11.3 What others could/should do to support carers

Participants were also asked what other support could or should be provided for carers. Carers who participated in the research were clearly very positive about the impact that NLCT has had on their quality of life. They were *“more than happy”* with the support provided. There was a view that other service providers, including GPs and other health professionals they came into contact with should be more proactive about recognising carers’ health and wellbeing issues and referring them for support wherever appropriate, as it doesn’t happen well enough at present. It was clear that NLCT was perceived to have made good progress in many respects, but there is still work to be done to ensure more hidden carers receive the support they need.

Greater official recognition of the caring role, and financial recompense for that, was also raised:

“The government could recognise carers more and pay them more, especially because of the financial impacts. Your caring role dictates what and when you can work. If other people had to do it, they would get more than we get.”

The fact that there will be a greater need for paid carers in future was highlighted by a professional stakeholder, as families are more geographically dispersed and cannot perform the caring role that many would assume otherwise, for example for ageing parents. The fact that paid carers can attend (albeit quickly so there is little time to listen to carers or cared for) four times a day if required, hospitals aim to set up a care plan prior to discharge and there is now an (albeit usually over-subscribed) patient at home service (where nurses, physiotherapists and Occupational Therapists, etc., can attend patients at home and do bloods, ECGs, etc., where they are comfortable and transport is not required). However, carers who gave their views did not highlight this degree of support for the cared for person or consequent positive impacts on them as carers, so whilst these positive improvements may be evident to some, there is still plenty of room for improvement so these filter down to carers.

3.11.4 Potential impact of the Carers (Scotland) Act

On 1 April, 2018, the Carers (Scotland) Act¹² comes into force. This legislation was designed to build on good practice happening in some parts of the country, such as North Lanarkshire, and ensure that all carers in Scotland are recognised and supported. For example, the Act establishes a duty on local authorities to provide support to carers based on their needs (within the parameters of national and local criteria according to guidelines which are to be set); produce a specific Adult Carer Support Plan and Young Carer Statement to identify carers’ need and personal outcomes; and to have its own information and advice service for carers which must at least provide information and advice on emergency and future care planning, advocacy, income maximisation and carers’ rights.

Professional stakeholders who participated in the research were aware of the Act but not necessarily familiar with the detail of it, so commented in more general terms. They were pleased that the profile of carers is being raised as they clearly need help and support. Whilst there was optimism around support at a national level via the legislation, and that this would be a positive step forward, there was still uncertainty around what difference it would actually make for carers in reality, on a day to day basis. What was perceived to be critical is that carers feel they have someone to speak to when they need to - someone with solutions to their problems and someone they feel *“has their back”*. If the Act does this, that will be

¹² <http://www.gov.scot/Topics/Health/Support-Social-Care/Unpaid-Carers/CarersBill> accessed 1/5/2017

appreciated, but there was not great confidence that would be the case. However, if carers know their rights, agencies need to be more accountable and carers are able to access those rights, then that will be an improvement.

4 Concluding comments

The purpose of this commission was to share North Lanarkshire Carers Together's learning and experience of the health and wellbeing needs of carers. The Carers Health Needs Survey which NLCT implemented from 2013 to 2016 and the supplementary qualitative research highlight the widespread, complex and inter-related issues facing carers in North Lanarkshire, and echo the issues identified in the national literature.

The Scottish Government recognises the important, and valuable, role that carers play - the Carers (Scotland) Act 2016 will be implemented in 2018. Whilst it is may be a natural reaction to look after loved ones, there is no doubt that unpaid caring can have a significant short and longer term effect on the health and wellbeing of carers, their quality of life, their relationships, their career and their finances. The Carers (Scotland) Act 2016¹³, aims to improve the quality, quantity and consistency of support provided to unpaid carers and a key element of this is the requirement for each local authority to provide an information and advice service for carers. The Act specifies that the information and advice service must provide information in particular about carers' rights, income maximisation, education and training for carers, advocacy for carers, health and wellbeing (including counselling) for carers, bereavement support services for carers following the death of a cared-for person, and emergency care planning and future care planning for carers.

This research clearly supports the importance of an information and advice service for carers. Carers need information and advice in order to exercise greater choice and control over decisions which affect them and those they care for. Carers are often too busy caring to seek support and it is difficult to know what support is available when *"you don't know what you don't know"*. But there is a critical first step which carers identified: actually being identified as a carer in the first instance. Without being identified as a carer (as many do not think of themselves in this way prior to engaging with NLCT) - and then receiving information, signposting or referral to other services and direct services from NLCT - they could not have accessed any of the support which they had received; and which had made a positive difference to their ability to continue to care and to their own health and wellbeing. This reinforces the importance of working closely with GP surgeries and the need to proactively seek out 'hidden' carers, working in a targeted way to support them.

The positive impacts of annual health checks were also highlighted. These have identified serious health issues for carers and encouraged others to pursue healthier lifestyles and access support to help them do so. A key issue here is the proactive nature of these health checks – when carers are busy and do not prioritise their own health and wellbeing issues, having a reminder to do so via an invitation to attend a health check is very powerful. This is doubly important as carers can often find it difficult to spend time on themselves and/or to ask for help, particularly for themselves. The fact that this proactive support shows carers that the work they do is recognised by authorities is also very important. Feeling recognised and knowing that they can access support if and when they need to do so – even if they don't access it – makes a big difference to how carers feel about themselves, the role they are playing and the wider 'system'.

North Lanarkshire has a higher than average proportion of carers and is the second highest area in Scotland in terms of carers providing 50+ hours of care per week. It therefore needs to make sure that there is sufficient investment in supporting unpaid carers to stay well and to sustain their caring role, rather than having to spend more resources on picking up the pieces for them and those they care for if they are not supported. The anticipated growth in the number of carers over the next decade or so reinforces the need to invest now in

¹³ <http://www.gov.scot/Topics/Health/Support-Social-Care/Unpaid-Carers/CarersBill> accessed 20 June 2017

preventative services to save both carer burnout and higher paid-for care costs in future. North Lanarkshire is not starting from scratch here as it has excellent, established carer support agencies, such as the NLCT team who are working with GPs to identify hidden carers and link them into a range of supports. The public sector in North Lanarkshire also has an excellent track record of incorporating carers' issues into strategies, policies and strategic structures so the carer's voice is heard. But there is still some way to go, so it is hoped that support for carers is protected from budget pressures and built upon in the lead up to the implementation of the Carers (Scotland) Act next year, to ensure North Lanarkshire's response is equal to the challenges facing its legion of unpaid carers.