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# Knowsley Joint Strategic Needs Assessment

## Adult and Young Carers

## **T h i s   r e p o r t**

This report has been prepared jointly by Knowsley Council, the Clinical Commissioning Group (CCG) and partners of the Knowsley Health and Wellbeing Board (HWB).

Its purpose is to provide an analysis of Vulnerable Adults in order to determine the following:

- How much impact does this issue have on local people?
- Can this impact be reduced through local action?
- Can local action reduce health inequalities?
- Will local action on this help address other issues too?

Understanding these things helps the HWB determine the level of priority that this issue should be given in the Borough's Health and Wellbeing Strategy.

This is one of a series of reports that comprise Knowsley's Joint Strategic Needs Assessment (JSNA), which will inform Knowsley's Health and Wellbeing Strategy.

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## 1. INTRODUCTION

### 1.1 Background

Carers play an important role in society and have particular challenges that they have to overcome. An enormous amount of personal and community care is provided by family and friends, and social care and health services should be seen in this context. Estimates of how much the equivalent cost of this informal support would be if carers' input had to be replaced run as high as £87 billion per year, which is nearly as much as total spending on the NHS.

Where services are needed to support people with illnesses, disabilities or addictions, the needs of informal carers should not be neglected, as they are closely linked, and often have a very important bearing on the effectiveness of the interventions for the cared for person.

The pressures on carers are such that that over time the effect on their health, social and financial wellbeing can be significant. Carers need support to continue to care - otherwise care can break down, with considerable cost to the individuals and to the health and care system.

The extract below from the Department of Health describes the vital importance of carers and the role they play in the community.

*'We do not need to understand each individual's circumstances or motivation in what is often a very personal and private activity but we do need to recognise the existence and the value of carers, both to the person they care for, and to the wider community.'*

*It is clear that carers enable many thousands of vulnerable people who need support, to continue to lead independent lives in their local communities. At the same time, carers reduce the amount of input that health and social services and other agencies need to make. It is essential that we act positively to protect the interests of carers and to foster a climate where they can continue to care for as long as they wish and are able to do so, without jeopardising their own health and wellbeing, financial security, or reducing their expectations of a reasonable quality of life.*

*We want to enable carers to make more choices for themselves and to have more control over their lives. We want services to recognise carers as individuals in their own right'*

*(Department of Health, Social Services and Public Safety, 2006)*

## 1.2 Methodology and Scope of this Needs Assessment

A Needs Assessment is a:

*“Systematic method for reviewing the health and wellbeing needs of a given population, leading to agreed commissioning priorities that will improve health and wellbeing outcomes and reduce inequalities<sup>9</sup>”*

The defined population for this Needs Assessment are carers living in Knowsley and the focus is on their needs not the individuals they care for. For the purpose of this Needs Assessment, a carer is defined as:

‘Anyone who cares, unpaid, for a friend or family member who (due to an illness, disability, mental health problem or an addiction) cannot cope without their support’. (Carers Trust, 2014).

This Needs Assessment was coordinated by the Whole Life Commissioning Team and Policy and Partnership Team in partnership with a wide range of stakeholders that work with Carers in Knowsley. This Needs Assessment assesses the needs of carers using existing reports, surveys, demographic and service data. Key informants provided additional information especially where existing data provided limited or no information.

The aim of this Carers Needs Assessment is to:

- Describe the number of carers in Knowsley and their needs
- Predict trends in the number of carers in the future and their changing needs to inform service development.
- Review the evidence-base around support for carers.
- Review current carer provision in order to identify gaps that can be addressed through the commissioning process.
- Highlight the key challenges for commissioners and providers of carers support

The Needs Assessment is written for commissioners in the Local Authority and Healthcare as well as stakeholders who provide services for carers including Primary Care, Secondary Care, Community Health and Social Care and Voluntary Groups.

### 1.3 National Policy and Guidance

National policy, strategy and legislation on carers have changed significantly over the last few years. The most significant change in the 2014 Care Act, which sets out a number of set duties on local authorities and other public sector organisations. Details of the developments are detailed below;

#### **The Care Act (2014)**

Under the Care Act, local authorities will take on new functions. This is to make sure that people who live in their areas:

- Receive services that prevent their care needs from becoming more serious, or delay the impact of their needs;
- Can get the information and advice they need to make good decisions about care and support;
- Have a range of providers offering a choice of high quality, appropriate services.

Importantly, the Act strengthens the rights and recognition of carers in the social care system, including, for the first time giving carers a right to receive services. These strengthen significantly the rights of carers and sets out clear duties for Local Authorities and other public sector organisations.

#### **Carers Strategy England 2008-2018 (2010)**

The Carers' Strategy has five objectives for carers to be achieved by 2018, so that carers will be:

- Recognised and supported as an expert care partner
- Enjoying a life outside caring
- Not financially disadvantaged
- Mentally and physically well, treated with dignity
- Children will be thriving, protected from inappropriate caring roles.

The Coalition Government refreshed this strategy in 2010 retaining these aims but inserting four priority areas:

- i. Supporting early self-identification and involvement in local care planning and individual care planning.
- ii. Enabling carers to fulfil their educational and employment potential.

- iii. Personalised support for carers and those receiving care.
- iv. Support carers to remain healthy.

### **Carers Strategy: The Second National Action Plan (2014-2016)**

This update to the national carers' strategy provided an overview of achievements since the last update in 2010 and sets out key actions for the next two years. Major progress in identifying and supporting carers is being brought about by the Care Act and the Children and Families Act and the update encourages a refresh of their local carer strategies to ensure all partners are signed up to the latest developments.

### **NHS Five Year Forward View (2014)**

The NHS Five Year Forward View recognises that, with an ageing population, increased long term conditions, and funding for health that is not keeping pace with demand, promoting well-being and preventing ill-health. Providing better support for carers is therefore critical to the future of the NHS. This follows on from NHS England's Commitment to Carers Policy.

### **The Children and Families Act (2013)**

In 2013, the Government tabled an amendment to the Children and Families Bill resulting in young carers being protected by law for the first time. This means that when a child is identified as a young carer, the needs of everyone in the family will be considered. This will trigger both children's and adult's support services into action – assessing why a child is caring, what needs to change and what would help the family to prevent children from taking on this responsibility in the first place. 5.3.1 NHS England Commitment to Carers Policy (2014)

This policy sets out how NHS England will support the NHS to deliver what carers have said is important to them. The document sets out a series of commitments to carers based on what carers outlined is important to them:

- *“Recognise me as a carer”*
- *“Information is shared with me and other professionals”;*
- *“Signpost information for me and help link professionals together”;*
- *“Care is flexible and is available when it suits me and the person for whom I care”;*
- *“Recognise that I may need help both in my caring role and in maintaining my own health and well-being”;*
- *“Respect, involve and treat me as an expert in care”;* and

- *“Treat me with dignity and compassion”.*

## 1.4 Local Policy and Strategy

The Strategy for Knowsley and the Joint Health and Wellbeing Strategy (JHWBS) are the overarching strategies for the borough, with the JHWBS setting the strategic direction to improve health and wellbeing outcomes. Improving the outcomes of carers is included in the Joint Health and Wellbeing Strategy but in addition there is a specific Carers Strategy that has been developed and is being implemented. Details are provided below;

### **The Knowsley Carers Strategy 2011 – 2014: A Life of My Own**

This strategy was produced as a result of extensive commitment and engagement of carers, young carers, former carers and carer representatives.

Carers decided what was important in their life and caring role and what needed to change to help them to continue to care for their loved ones and to have a life of their own.

Over the course of the last four years carers have had a greater opportunity to influence how they are supported, what services they needed and the direction of carer services in Knowsley. Some examples include:

- The development and introduction of a Carers Personalised Break Scheme for carers and carers of people with a mental illness.
- The development of a new carer focused assessment and support planning process.
- The introduction of a range of ‘wellbeing’ activities that aim to reduce carer social isolation, provide peer support and help the carer in their caring role. Activities include: Spa days and pamper activities, men only activities, activities for young adult and working carers.
- The formation of the Carers Vision Group: This is a Group of carers who have been provided with training in facilitating and presentation. They attend a range of training and events to give the carers point of view.
- The formation of the Carers Strategy group: Carers, former carers and representatives from organisations who work with carers meet on a monthly basis to drive the implementation of the Carers Strategy. The group is responsible for reviewing the quality of carer services and making recommendations on how available funding should be allocated.
- The formation of the Carers Partnership Board. This is the group that oversees the implementation of the Carers Strategy. Consists of carers, carer representatives, members of key community organisations and officers of the Council. The Group is a key link in the governance and decision making that impact on carers in the Borough.

Since the publication of the Knowsley Carers Strategy 2011-2014: A Life of My Own, adult and young carers have been engaged and involved in identifying and defining their own needs and the outcomes they want to

achieve to be able to continue with their caring role and have a quality life of their own.

### **Knowsley Carers Strategy Refocus 2014-17**

Knowsley's Carers Strategy will plan and deliver services that reflect the new priorities for carers in Knowsley. It is a strategy for all carers including parents of disabled children, young people and sibling carers (under 18 years of age). Through regular consultation and involvement on working groups and events, carers, ex-carers and their representatives have said what is important to them, and what they need to continue caring for their loved ones.

## **1.5 National Outcome Frameworks**

Carers are a priority for Social Care, Public Health and the NHS. This is reflected in all three outcome frameworks, especially the Social Care Outcome Framework.

### **1.5.1 Social Care Outcome Framework:**

- 3B: Overall satisfaction of carers with social services
- 3C: The proportion of carers who report that they have been included or consulted in discussions about the person they care for.
- 3D: The proportion of people who use services and carers who find it easy to find information about support

Also, inextricably linked to a number of other social care outcomes including;

- Permanent admissions to residential and nursing care homes per 100,000 population.

### **1.5.2 Shared Outcome between the NHS and Adult Social Care Framework:**

- Carer-related quality of life

### **1.5.3 Shared Outcome between the Public Health and Adult Social Care Framework:**

- Proportion of people who use services and their carers, who reported that they had as much social contact as they would like.
- Proportion of adults with a learning disability who live in their own home or with their family.
- Proportion of adults in contact with secondary mental health services living independently with or without support.

These outcomes will measure the success of services in supporting carers and will provide an indication of how the NHS, Public Health and Social Care are working together to support carers locally.

## 2. ASSESSING LOCAL NEEDS

To understand the local needs of carers it is important to first identify how many carers there are and their characteristics.

### 2.1 Carers in Knowsley

In the 2011 Census, 17,865 Knowsley residents described themselves as unpaid carers. This represents 12.2% of the Borough's population and is higher than the national and regional figures (10.2% and 11.1% respectively), but lower than the St Helens and Wirral figures (12.9% and 12.6% respectively).

Table 1: Total numbers of unpaid carers according to Census figures

	ALL people who provide unpaid care					
	2001		2011		2001/11 change	
	Total providing unpaid care	% of total population	Total providing unpaid care	% of total population	Change in total providing unpaid care	% point change in total providing unpaid care
Knowsley	17,348	11.6	17,865	12.2	517	0.6%
Liverpool	47,711	11.2	50,562	10.8	2,851	0.4%
Sefton	32,639	11.7	34,547	12.6	1,908	0.9%
St. Helens	21,494	12.3	22,591	12.9	1,097	0.6%
Wirral	37,402	12.1	40,340	12.6	2,938	0.5%
England	4,854,731	10.1	5,430,016	10.2	575,285	0.2%
North West	722,119	10.9	781,972	11.1	59,853	0.2%

The overall proportion of unpaid care remained broadly the same between 2001 and 2011; however the *extent* of care being provided has increased, with increases in the proportion of people providing 20-49 hours & 50 or more hours of unpaid care per week over this period. Conversely, the proportion of unpaid carers providing care for between 1 to 19 hours per week has decreased. This is pattern is replicated across the North West and England, including local authorities within Merseyside.

Table 2: Hours of unpaid care provided per carer a week in Knowsley

<b>Knowsley</b>	<b>Census 2001</b>	<b>Census 2011</b>	<b>% change</b>
Provides unpaid care (total) <i>% total population</i>	11.6%	12.2%	0.6%
Provides 1 to 19 hours unpaid care a week <i>% of unpaid care (total)</i>	52.6%	49.2%	-3.4%
Provides 20 to 49 hours unpaid care a week <i>% of unpaid care (total)</i>	16.8%	18.0%	1.2%
Provides 50 or more hours unpaid care a week <i>% of unpaid care (total)</i>	30.6%	32.9%	2.3%

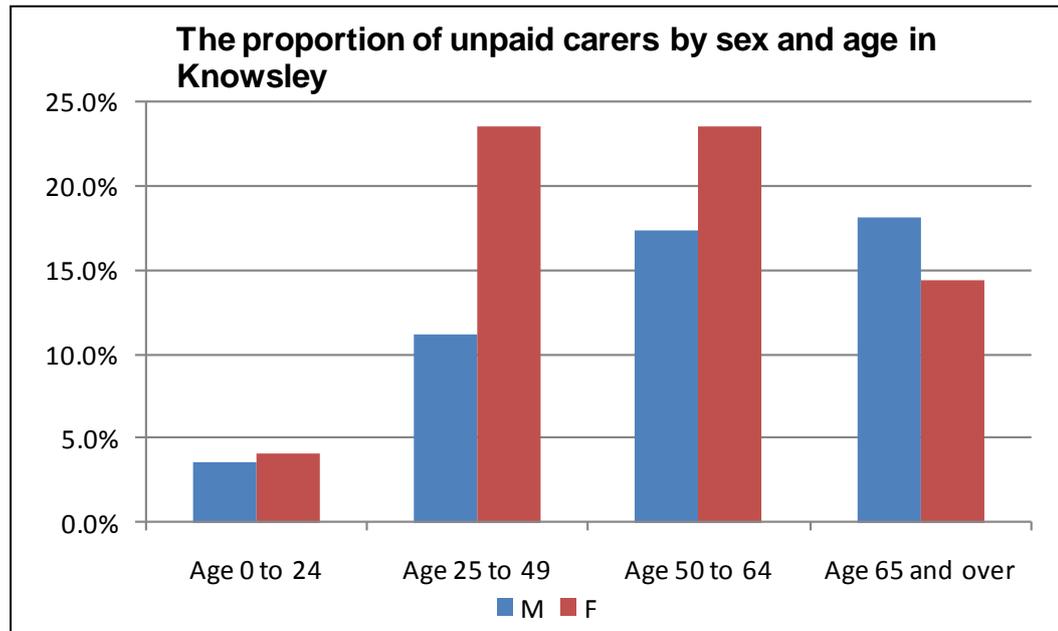
The amount and type of care that carers provide varies considerably. A carer might provide a few hours of care a week, perhaps shopping for a friend or relative, or they may care around the clock. Providing care can range from helping with household tasks on a regular basis to providing continuous care.

## 2.2 Characteristics of Carers

### 2.2.1 Gender and age

Of the 17,865 unpaid carers in Knowsley, 10,469 (58.6%) are female and 7,395 (41.4%) are male. This is a similar proportion seen regionally and nationally.

Figure 1: The proportion of unpaid carers by sex and age in Knowsley



In Knowsley, the highest proportion of unpaid carers (11.3%) is women aged 50 to 64 providing 1 to 19 hours of unpaid care per week. This equates to 11.3% of female unpaid carers.

Overall, more women provide 50 or more hours in unpaid care with 3,443 women and 2,442 men respectively. However, men aged 65 and over have the highest proportion of 50 or more hours on unpaid care per week with 56.7%. However, this is equivalent to 982 men, which is marginally lower than the corresponding number of women of the same age with 993.

Table 3: Male unpaid carers by age and amount of unpaid care provided a week

Males				
Age	Provides unpaid care			
	Provides unpaid care: Total	Provides 1 to 19 hours unpaid care a week	Provides 20 to 49 hours unpaid care a week	Provides 50 or more hours unpaid care a week
<b>All categories:</b>	7,395 (100.0%)	3,625 (49.0%)	1,328 (18.0%)	2,442 (33.0%)
<b>Age</b>				
Age 0 to 24	822 (100.0%)	570 (69.3%)	160 (19.5%)	92 (11.2%)
Age 25 to 49	2,487 (100.0%)	1,409 (56.7%)	485 (19.5%)	593 (23.8%)
Age 50 to 64	2,353 (100.0%)	1,164 (49.5%)	414 (17.6%)	775 (32.9%)
Age 65 and over	1,733 (100.0%)	482 (27.8%)	269 (15.5%)	982 (56.7%)

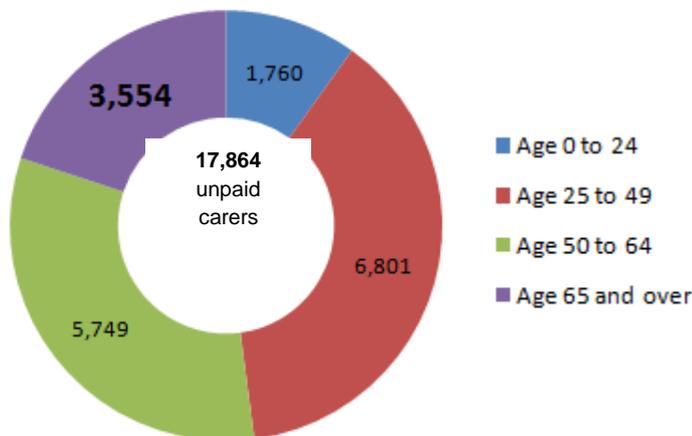
Table 4: Female unpaid carers by age and amount of unpaid care provided a week

Females				
Age	Provides unpaid care			
	Provides unpaid care: Total	Provides 1 to 19 hours unpaid care a week	Provides 20 to 49 hours unpaid care a week	Provides 50 or more hours unpaid care a week
<b>All categories: Age</b>	10,469 (100.0%)	5,157 (49.3%)	1,879 (17.9%)	3,433 (32.8%)
<b>Age 0 to 24</b>	938 (100.0%)	599 (63.9%)	195 (20.8%)	144 (15.4%)
<b>Age 25 to 49</b>	4,314 (100.0%)	2,379 (55.1%)	735 (17.0%)	1,200 (27.8%)
<b>Age 50 to 64</b>	3,396 (100.0%)	1,639 (48.3%)	661 (19.5%)	1,096 (32.3%)
<b>Age 65 and over</b>	1,821 (100.0%)	540 (29.7%)	288 (15.8%)	993 (54.5%)

Knowsley has a higher number of young carers aged 0-24 (10% locally compared to 7.5% nationally). Recent calculations nationally suggest that the number of young carers is likely to be 4 times more than reported in the census, which would put Knowsley’s figure closer to 1400.

In Knowsley, 3,554 people who provide unpaid care were aged 65 and over, which equates to 19.9% of all unpaid carers. This is lower than both the regional figure of 21.4% and the national figure of 22%. It can be assumed that those aged over 65 are likely to need some additional support from the Council to support them in their caring role.

Figure 2: Age distribution of unpaid carers in Knowsley

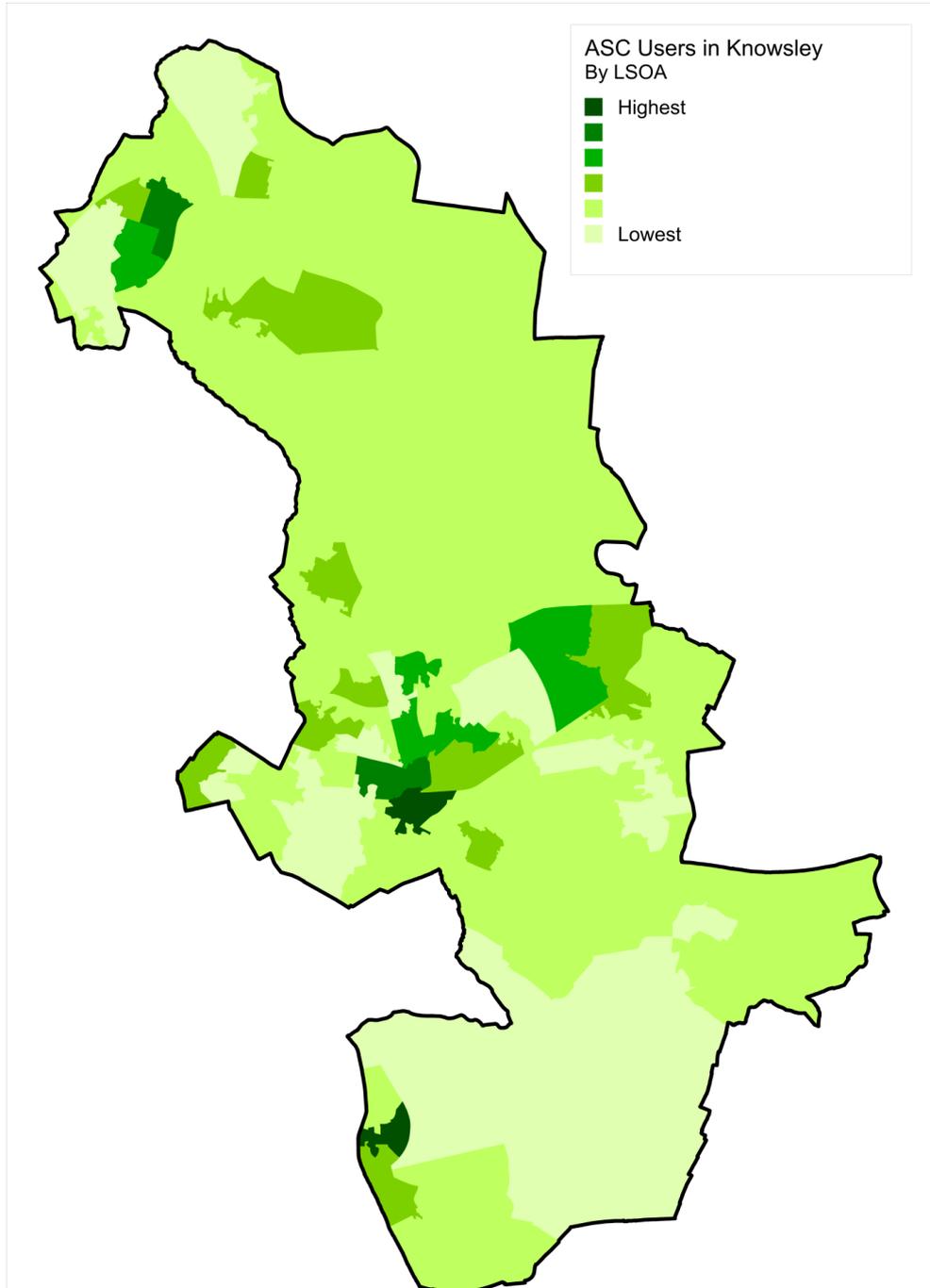


*NB: due to the composition & nature of the data-sets generating the overall information, each category is mutually exclusive; therefore the volumes of unpaid carers within each category must be regarded independently of the other.*

## 2.2.2 Location of carers - Where do carers live?

The map below shows the location of residences for carers in Knowsley and the darker areas represent those locations where the number of carer's residences is higher.

Areas of Huyton and Halewood show the highest concentrations of home residences of carers.

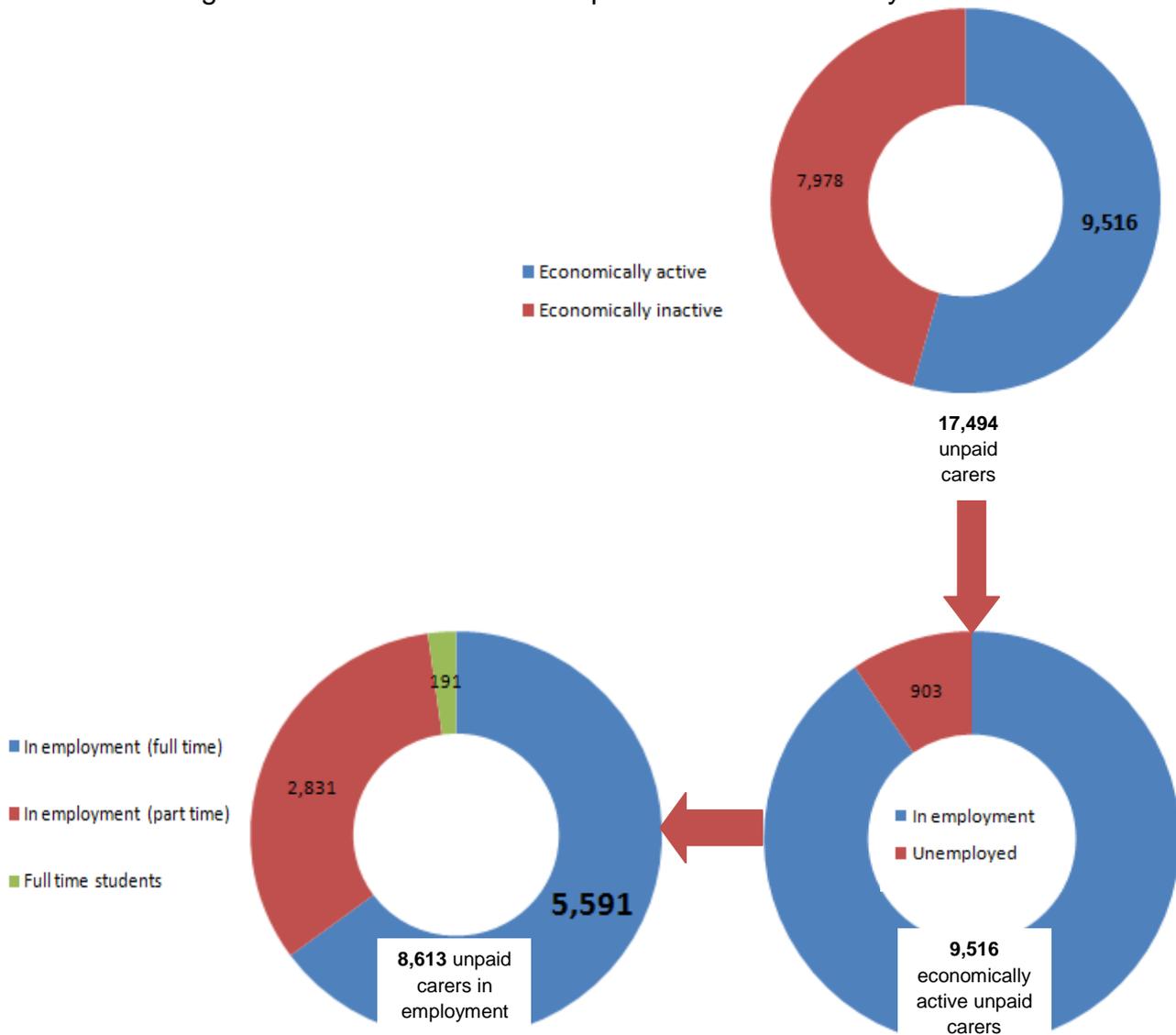


### 2.2.3 Economic Status of Carers

Economically active people are defined as those people who are in employment and those people who are unemployed and are available to work.

Economically inactive people are defined as those people who are not in employment or those people who are not available to work. This includes people who are retired, those looking after family, those who are long term sick and some students.

Figure 3: Economic status of unpaid carers in Knowsley



In Knowsley, 9,516 unpaid carers are economically active, which is equivalent to 54.4% of all unpaid carers. This is lower than the regional average of 56.8% and the national average of 57.9%. Of the economically active unpaid

carers in Knowsley, 8,613 unpaid carers are in employment, which is equivalent to 49.2% of all unpaid carers.

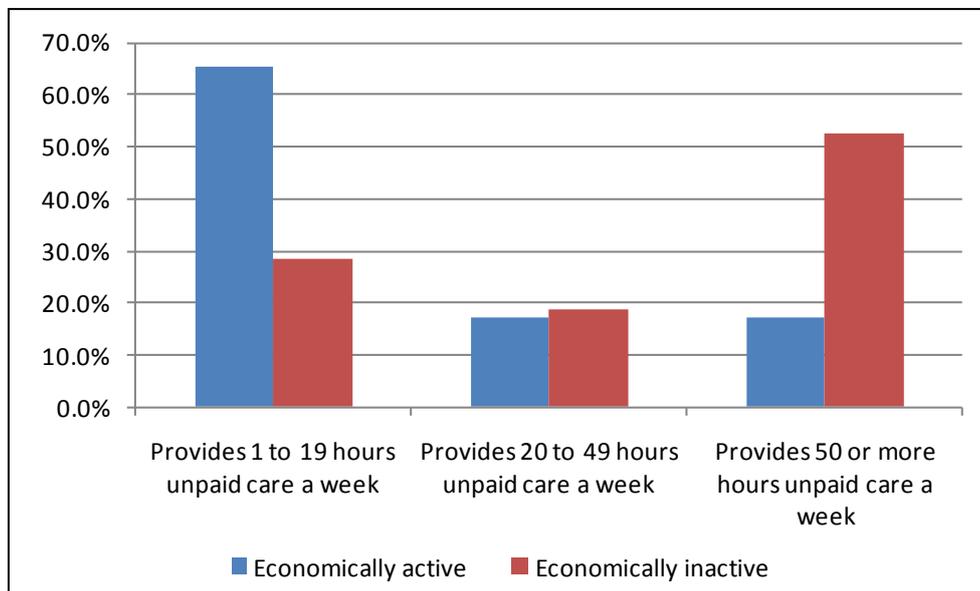
It can be assumed that carers who are also in full time employment may also require support in their caring role. Of the employed unpaid carers in Knowsley, 5,591 carers are in full time employment, which equivalent to 32% of all unpaid carers. This is a lower proportion than the regional average of 34.1% and the national average of 46.9%.

1,107 unpaid carers are economically inactive (long-term sick/disabled) and 191 carers are also in full time education (it is not however clear how many of these are young carers). We can also assume that these carers may need support in their caring role.

Assuming that Carers who also have a full time job, are in full time education or are economically inactive due to illness or disability are more likely to need support to fulfil their caring role, we can assume that there are 6,889 carers in Knowsley who fit into this category.

The following chart shows that proportionately more economically inactive unpaid carers provide 50 or more hours of unpaid care per week; conversely, proportionately more economically active unpaid carers provide 1 to 19 hours of unpaid care per week.

Figure 4: Economic activity by hours of care provided



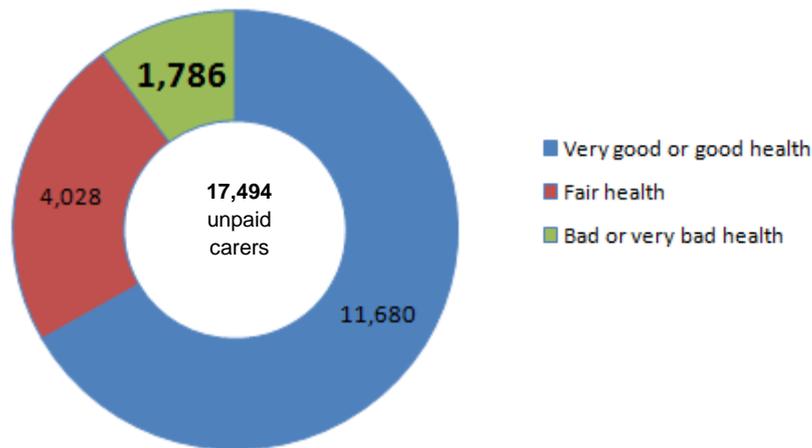
It can be assumed that those carers who are in employment and also providing 50 or more hours of care are likely to be in need of support from the local authority in their caring role. It is likely that many of these carers are currently unemployed. However, the difference in percentage between those currently unemployed (10%) and those economically active providing 50 or more hours of care (17%) shows that there are a number of carers who are also in part or full time employment.

### 2.2.4 Health Status of Carers

In Knowsley, 11,680 people who provide unpaid care reported very good or good health, which equates to 66.7% of all unpaid carers, 4,028 people who provide unpaid care reported fair health, which equates to 23% of all unpaid carers.

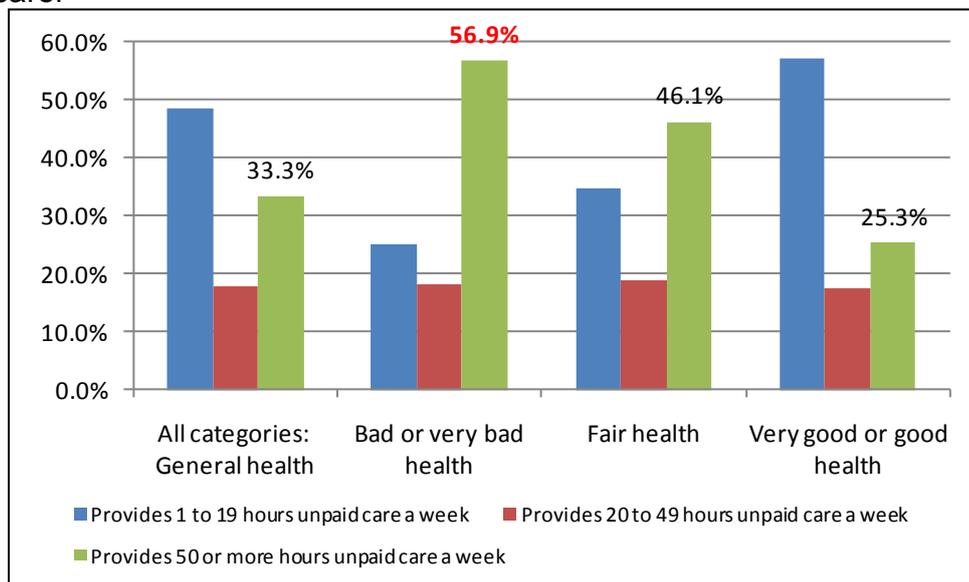
However, 1,786 people who provide unpaid care reported bad or very bad health, which equates to 10.3% of all unpaid carers. This proportion is higher than both the regional figure of 7.8% and the national figure of 6.7%.

Figure 5: Health status of unpaid carers in Knowsley



The following Chart shows how the hours of care provided vary according to the carer’s general health. People providing 50 or more hours of unpaid care increase as their general health worsens: 56.9% with bad or very bad health provide 50 or more hours, as against only 25.3% of those with very good or good health. This may be an effect of age – as people get older, their health may worsen though they may find themselves having to provide care for other household members.

Figure 6: Number of hours of unpaid care provided weekly by general health of carer

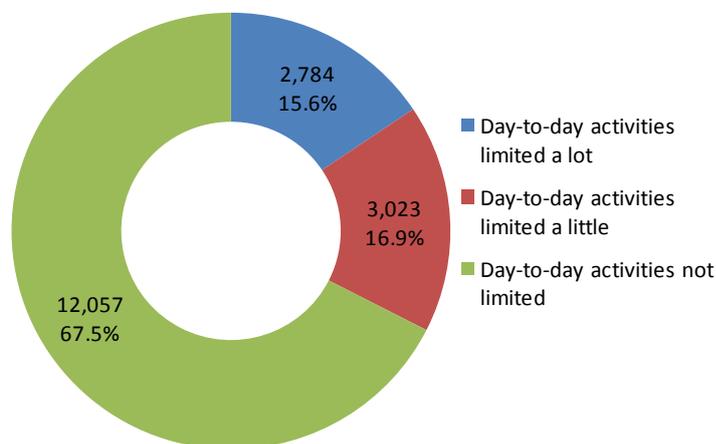


It can be assumed that carers who also report bad or very bad health themselves are likely to need additional support in their caring role and/or are accessing support to address their own health and wellbeing needs. In Knowsley there are 1,786 carers who report having bad or very bad health and it is this group of carers who are also providing the most hours of care 56.9%.

#### 2.2.4.1 Carers with Long-Term Disabilities

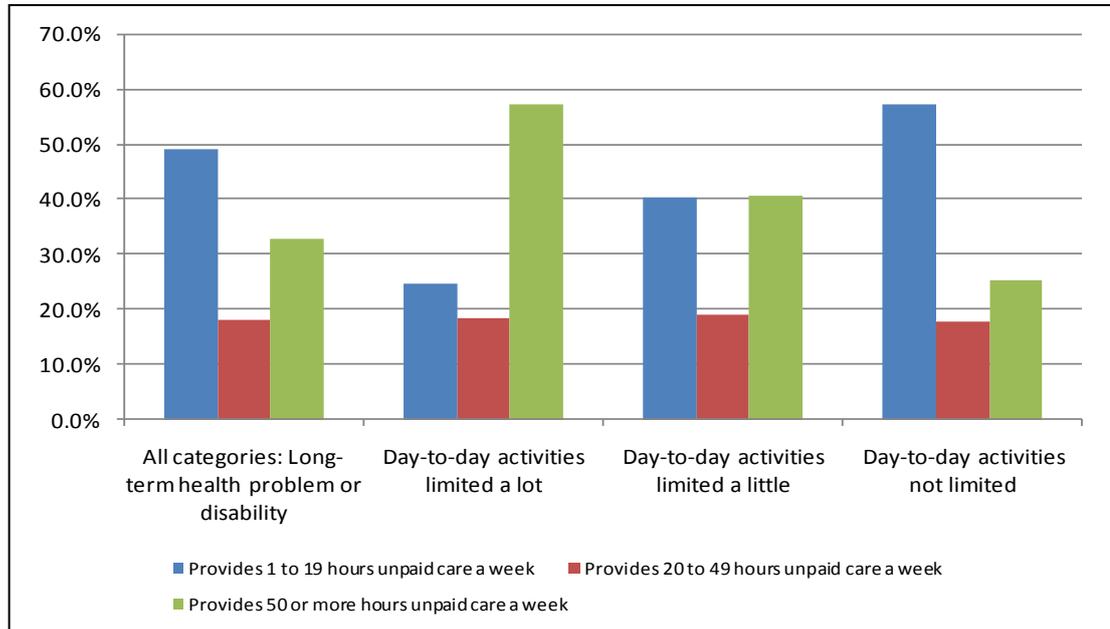
The following chart shows the proportion of unpaid carers reporting a long-term disability, which limits their day-to-day activities either a lot or a little. 67.5 % of unpaid carers did not report a long-term health problem/disability, (limiting their day-to-day activities), whereas 2,784 (15.6%) reported a long-term health problem/disability, which limited their day-to-day activities a lot.

Figure 7: Proportion of unpaid carers with long term disabilities



The following chart correlates the hours of care provided by an unpaid carer with the long-term health problem/disability that limits the person's day-to-day activities. The chart shows that the greatest proportion of unpaid carers whose day-to-day activities are limited a lot, are those who provide 50 or more hours of unpaid care per week. These carers are more likely to need additional wellbeing and health support to maintain their caring role.

Figure 8: Proportion of unpaid carers with long term disabilities against amount of unpaid care a week provided.



Conversely, the majority of unpaid carers whose day-to-day activities are not limited by long-term illness/disability are those who provide 1 to 19 hours of unpaid care per week.

### 2.2.5 Future Demand – Projecting Number of Carers and Support Needed

In England and Wales, the number of carers increased from 5.2 million to 5.8 million between 2001 and 2011 (ONS, 2011). The greatest rise has been amongst those providing over 20 hours care, which can have a significant impact on the health and wellbeing of the carer, including their ability to retain paid employment alongside their caring responsibilities. It is predicted that the number of carers will increase significantly to 9 million by 2037 (Carers Trust, 2014).

The number of carers in the Borough and their needs are likely to change dramatically over the next ten years and beyond. Population changes will mean that there will be an increasing number of people that will require support from a carer. Below highlights the changing population demographics and how this will have an impact.

#### (i) Increase in Ageing Population

The number of people aged over 50 in the Borough is expected to increase by 15.1% between 2009 and 2019. This means:

- There will be an additional 7,500 people aged over 50 by 2019.

- The greatest proportion increase is anticipated to occur in the 85 and over, age group where an additional 1,200 people are expected to be residing in the Borough by 2019 (a 51.5% increase).
- By 2019 the overall older people's dependency ratio on those of working age in Knowsley will be larger than the child dependency ratio.

The implications of an ageing population are three fold in relation to carers,

- There will be more people requiring caring support because of age-related conditions
- There will also be potentially more old carers, who will have their own needs to meet also and thus may find it more difficult to care for others.
- The older people's dependency ratio will potentially mean that there are less working age people available to provide the carer support.

#### **(ii) Increase in dementia prevalence**

A particular issue for Knowsley will be dealing with the rising rates of dementia. By 2015 the number of people suffering from dementia in Knowsley is expected to grow to 1,958. Of this figure around 11% of cases are expected to be severe. The 2010 figure stands at 1,824. During the later stages of ageing the problems of dementia increase rapidly. The future expansion of services for dementia sufferers and their carers will present special challenges to the health and social care system, particularly where a greater proportion of the population are choosing to live alone.

#### **(iii) Increase in survival rates**

More people living longer and surviving with chronic diseases and complex care needs, which requires a different approach to longer term care and a new way of supporting people to manage illness. The impact in Knowsley is likely to be greater than National as the Borough currently experiences high levels of poor health. Areas with previously poor health are characterised by an effect described as "adding years to life but not life to years", which points out the impact of people growing old with long-term limiting conditions. Life is prolonged but without health improvement, resulting in an associated demand for all health and social care services.

Therefore, an increase in the number of people requiring care is expected.

#### **(iv) Potential decrease in people undertaking caring roles**

While the number of people needing care is set to rise, social trends could, in the future, have an effect on the number of available carers. The growth in the number of lone parents, falls in birth rates, higher divorce rates, the increase in the numbers of people living alone and greater family mobility may all have an impact on the numbers of people available to assume a caring

role. In addition, the growing number of women who are employed outside the home will have implications for the number of carers, since women have traditionally fulfilled the caring role.

#### **(v) Welfare reforms and public sector funding reductions**

Welfare reforms and a significant reduction in public sector funding are increasingly creating significant challenges. Welfare reforms are having a direct impact on carers through reductions in housing, welfare and benefits support to themselves and individuals with disabilities / caring needs exacerbating existing financial pressures. In addition, an increasing demand for support services alongside a significant reduction in public sector funding means that services to support carers and those that they care for are likely to be reduced putting potentially extra strain on carers.

### **2.3 Carers Health and Wellbeing Needs**

Carers' needs are complex and vary dependent upon the individual's personal circumstances, including the amount and type of caring needs of the person they care for, their individual living and working conditions, their age and family set up amongst other things. Indeed, some carers are at a greater risk of being disadvantaged or becoming ill themselves than other carers. It is therefore important to recognise and respond to those that are at greatest risk whilst at the same time there are general support needs that are applicable to all carers.

#### **(i) Overall Carers Needs**

There are significant risks associated with caring and maintaining good health and positive wellbeing. These include risks to physical health (strain, injury, exhaustion and lack of sleep), mental health (stress, anxiety, worry and depression) and financial pressures (loss of income from paid employment). Many carers also experience social isolation and find it difficult to maintain relationships and social networks due to the impact of caring for someone. Carers can also receive inadequate support from services to help them with their caring role, resulting in illness and limited support to help them recover.

The Carers Trust estimated that the unpaid work and support that carers give save the UK purse £119 billion a year. In Knowsley the cost of a single carer having to stop caring could result in additional residential care home costs of over £13,000 per year for each person previously cared for.

The Royal College of General Practitioners (RCGP) 'Supporting Carers in General Practice Guide' states that:

- Up to 40% of carers experience psychological distress or depression.

- Carers have an increased rate of physical health problems, for example, providing high levels of care is associated with a 23% higher risk of stroke.
- Older carers who report 'strain' have a 63% higher likelihood of death in a year than non-carers or carers not reporting strain.
- One in five gives up work to care, and
- More than half of carers fall into debt as a result of caring.

## (ii) Which Carers are at Greatest Risk of Ill Health?

National evidence and local intelligence has been used to identify carers who have the greatest health and wellbeing needs and are at a higher risk of becoming ill due to their caring responsibilities.

Using the 'at risk' determinants of: economic activity, health, age and no of hours of unpaid care provided per week, the following 'sub-set' of unpaid carers has been identified as being potentially 'at risk' and therefore likely to need additional wellbeing and health support in their caring role.

<b>Unpaid Carers at Risk</b>	
Economically active (FT employment)	5,591
Economically inactive (long-term sick/disabled)	1,107
Health (bad or very bad health)	1,786
Health (long-term disability)	2,784
Providing 50 or more hours of care/week	5,833
Age (65+)	3,554

Furthermore, the Knowsley Carers Strategy Refocus identifies those of working age, and particularly those aged 50- 64, as being at risk; in Knowsley the highest proportion of unpaid carers (11.3%) are women aged 50 to 64 providing 1 to 19 hours of unpaid care per week.

The Strategy also identifies male carers and young adult carers to be at risk.

National evidence also shows the following groups to be at risk and these also apply to Knowsley:

- Black, Asian and Minority Ethnic Groups
- Young people with parents experiencing mental health problems and drug and alcohol problems.
- Carers of individuals with dementia

## (iii) Young Carers Needs

Young carers are children and young people who often take on practical and/or emotional caring responsibilities that would normally be expected of an adult. The tasks undertaken can vary according to the nature of the illness or disability, the level and frequency of need for care and the structure of the family as a whole. A young carer may do some or all of the following:

- Practical tasks, such as cooking, housework and shopping.
- Physical care, such as lifting, helping a parent on stairs or with physiotherapy.
- Personal care, such as dressing, washing, helping with toileting needs.
- Managing the family budget, collecting benefits and prescriptions.
- Administering medication
- Looking after or “parenting” younger siblings.
- Emotional support
- Interpreting, due to a hearing or speech impairment or because English is not the family’s first language.

Some young carers may undertake high levels of care, whereas for others it may be frequent low levels of care. Either can impact heavily on a child or young person. (*Carers Trust, 2014*)

Figures from the 2011 Census show that there are 166,363 young carers in England, compared to around 139,000 in 2001; however this is likely to be an under representation as many remain unidentified and unnoticed.

If left unsupported young carers can take on responsibilities that will have a lasting effect on their health and wellbeing, friendships and life opportunities. Many young carers experience issues with:

- Physical health: often severely affected by caring through the night, repeatedly lifting a heavy adult, poor diet and lack of sleep.
- Emotional wellbeing: stress, tiredness and mental ill-health are common for young carers.
- Isolation: feeling different or isolated from their peers and with limited social opportunities.
- Lack of a stable environment: traumatic life changes such as bereavement, family break-up, losing income and housing, or seeing the effects of an illness or addiction.

- Knowsley has a higher number of young carers aged 0-24 (10% locally compared to 7.5% nationally).

This group is a particularly vulnerable cohort as the level of care they provide would usually be undertaken by an adult and as a result, this has a significant impact on their normal childhood and therefore their mental health and wellbeing. Although there is no robust evidence to show long-term emotional or mental health problems associated with caring, it is known that young carers occur more frequently within single parent families and can often face isolation and social exclusion with little support from other family members.

Young carers are also less likely to discuss their caring responsibilities, with research showing this secrecy may be due to a fear of social service intrusion, associated stigma or through loyalty to the person they are caring for.

The wider impacts of these effects can also be seen on a [young carer in their education](#), [employment](#) and their [health and wellbeing](#). A report by the Children's Society (2013) highlights that:

- One in 12 young carers is caring for more than 15 hours per week.
- Around one in 20 misses school because of their caring responsibilities.
- Young carers are 1.5 times more likely than their peers to be from black, Asian or minority ethnic communities, and are twice as likely to not speak English as their first language.
- Young carers are 1.5 times more likely than their peers to have a special educational need or a disability.
- The average annual income for families with a young carer is £5,000 less than families who do not have a young carer.
- There is no strong evidence that young carers are more likely than their peers to come into contact with support agencies, despite government recognition that this needs to happen.
- Young carers have significantly lower educational attainment at GCSE level, the equivalent to nine grades lower overall than their peers e.g. the difference between nine B's and nine C's.
- Young carers are more likely than the national average to be not in education, employment or training (NEET) between the ages of 16 and 19.

### 3. CARERS AND STAKEHOLDER INSIGHT

Nationally and locally there has been significant insight gathered on the specific needs of carers and the types of support they need.

#### 3.1 National Views of Carers

A national survey (Carers UK State of Caring Survey 2014) of nearly 5,000 carers showed that more than 80% of carers feel that caring has a negative effect on their health.

- 69% of carers find it difficult to get a good night's sleep as a result of caring,
- 58% have reduced the amount of exercise they do since they started caring,
- 82% feel more stressed, and,
- 73% feel more anxious because of their caring role.

The survey also showed that one in five (19%) of carers felt their caring role was ignored and not recognised by health professionals.

Overall, almost two-thirds (61%) felt that they had reached 'breaking point', unable to carry on without a change in their circumstances.

This survey was followed by a Carers Manifesto (Carers UK, 2014) that set out what good support would mean for carers and what they want. It identified the following;

#### **In terms of income and finances, carers want:**

- To be able to maintain financial resilience which enables them to have a life alongside caring and which means they aren't left in debt, with little or no savings and facing financial hardship into retirement.
- For carers' benefits to recognise their huge contribution to society rather than highlight how poorly valued they are.
- A social security system which supports rather than prevents carers working or studying alongside caring.
- For all financial support to rise with the cost of living and for the additional costs of caring in household bills and transport costs to be recognised through additional support.

#### **In terms of health and care, carers want:**

- Good quality, reliable and affordable care services which enable them to have a life alongside caring.

- Health and care services which recognise carers as expert partners in care.
- Health services which recognise that carers' have their own health needs and provide flexible support which proactively seeks to reduce carer ill-health.
- Reform of funding for social care

**In terms of employment and training, carers want:**

- To have access to good quality, reliable and affordable replacement care services so they can have confidence in the care being provided whilst they are at work.
- Flexible, understanding employers who recognise the value of supporting carers to combine work and caring.
- Rights at work which recognise and value caring as much as other family responsibilities and allow carers time off to care.
- Support to return to work when caring comes to an end.
- A benefits system which supports carers to work or study alongside caring, rather than makes it harder.

**In terms of recognition, information and advice, carers want:**

- Their role to be recognised and respected as a crucial part of society.
- Government and the media to proactively combat myths about families receiving disability and carers benefits.
- Advice, information and support to be easily accessible wherever carers are, rather than them having to seek it out. Health and social care professionals, workplaces and community settings should work to identify carers and guide them to support.
- Caring to be given the same political and economic prominence as becoming a parent – so that 'supporting families' financially, through services and in workplaces is not just about childcare but about caring across the life course.

### **3.2 Local Views of Carers and Wider Stakeholders**

Local views of carers and wider stakeholders are regularly collated through the Carers Partnership Board and other engagement and service activities to help shape services and programmes. This includes carers being involved in the co-production and quality monitoring of carer services and in local policy through the Carers Partnership Board.

There is also an annual carers survey that is conducted in Knowsley with carers. In addition, there has been specific insight gained to help inform and shape the Knowsley Carers Strategy.

Below provides an overview of the insight gained.

### 3.2.1 Adult Carers Survey

The Knowsley Adult Carers survey was undertaken in 2014 and as well as asking questions used to compare areas across the UK it also used additional questions to further develop the profile of caring in Knowsley.

From the 1219 carers overall, a survey was sent at random to 977 addresses and from this 311 responses were received. Some of the responses are listed below:

- 32% of respondents said they were extremely satisfied with the care and support services they received;
- 68% said they were helped by care and support services to stay in contact with people;
- Only 25% of those who completed the survey said they found accessing information about things such as support or data was easy to find.
- 46% said they were quite anxious and depressed in general
- Almost half said they had adequate control over their lives
- Only 2% felt they had a bad quality of life

### 3.2.2 Knowsley Carers Strategy Refocus 2015-2017

From October 2014, engagement has been undertaken with adult and young carers from across Knowsley to revisit their priorities to inform the Carers Strategy Refocus. There is much to do to put what people need into practice and this cannot all be achieved at the same time. The information set out in the Carers Strategy Refocus Action Plan is based on the priority outcomes that carers want to see happen first.

#### **Carers in Knowsley want:**

- To be fully involved in the assessment of the person they care for and are treated as a partner in the development of support plans.
- Regular personalised breaks suited to the individual situation. They want to spend quality time for themselves, their family and friends.
- Having the chance to talk about their experiences and the emotional support they need

- The opportunity to take part in normal family life, social activities, leisure, education and be part of the community.
- Not to be financially disadvantaged because of their caring role.
- To be kept fully informed and involved when the person they care for is in hospital, and their discharge arrangements.
- Access to GP and Community Health services that are more flexible and understanding of carers needs.
- Young adult carers want the right support to access further education, voluntary work and employment.

#### **Young Carers in Knowsley want:**

- To make sure that they are fully involved in assessments that affects them and their family.
- To have time to away from their caring responsibilities: time for themselves, with family, with friends, with other carers.
- To get the information they need in the way that they want it.
- To help to do well at school.
- To help get further education or go to work
- To get a better service from GP and health services
- To get through the period of transition between children and adult support services
- To be protected from inappropriate caring and have the support they need to learn, develop and thrive and to enjoy positive childhood

Through the engagement activity for the Knowsley Carers Strategy Refocus 2015-2017 carers themselves acknowledged that key groups of carers were under represented in accessing carer services. Male carers, working carers, young adult carers and young carers were seen as key groups that were hidden and the strategy refocus aims to address this need.

### **3.2.3 Other sources of local insight**

There has been ongoing dialogue with carers about their needs and the support they receive through various means, including the Carers Partnership Board and targeted activities as part of the annual co-production of the Adult Social Care Local Account. During 2015, the positive experiences and key issues raised by carers and wider stakeholders include the following;

- Positives expressed about the support provided by the Knowsley Carers Centre and Kirkby Day Centre
- Concerns and issues have been raised in respect to the following;
  - The negative impact the revised 'transport policy' (Travel Support Policy – Adult Social Care) in having on carers and the cared for.

- The scale of increases in charges for day services, and the specific impact this is having on carers who may have to leave work as result.
- A feeling that despite Carers have been told that they are recognised for the work , carers do not feel valued by the actions taken by commissioners.
- Carers want to be consulted and communicated early about changes in services and support packages.
- Some carers have expressed that they feel ill-informed about social care services available, developments and changes being implemented
- Issues regarding the carers assessment process and the way it is delivered and how it makes the carer feel.
- Inconsistencies in approaches of social care workers and attitudes / culture

Specific issues have been raised around length of time to access support for the cared for, such as access to Knowsley Access team, Educational support, and housing issues

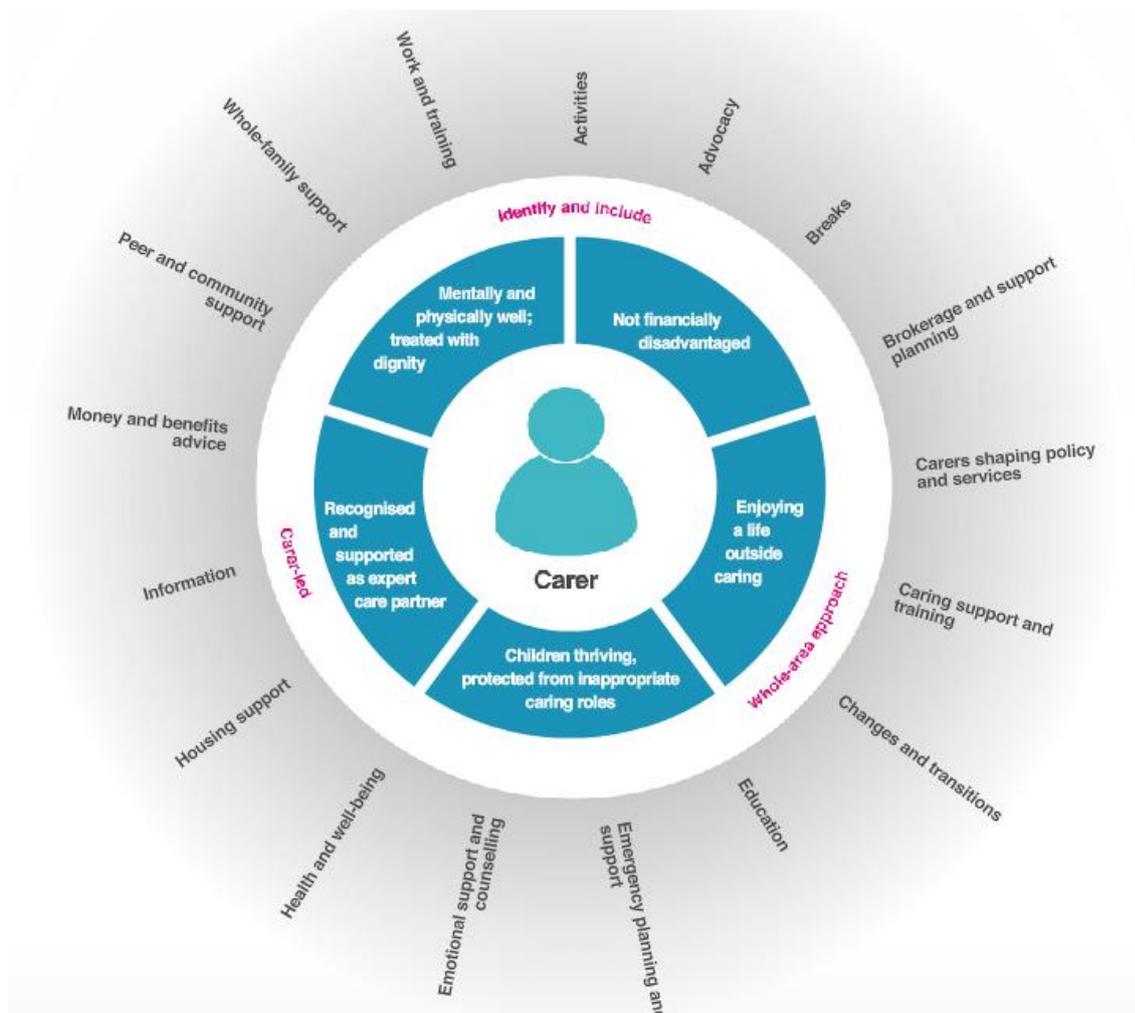
## 4. EVIDENCE OF WHAT WORKS

There are a number of national sources of evidence and guidance on the types of services, support and interventions that have a positive impact on carers. Below is a brief summary of the evidence.

### 4.1 National Evidence and Guidance

#### 4.1.1 The Carers Trust

The Carers Trust provides extensive resources for the effective commissioning of services to support carers. The Carers Hub (below) is an interactive model based on the outcomes of the National Carers Strategy for England and contains practical guidance and innovative examples of service design and delivery.



#### 4.1.2 The Royal College of General Practitioners (RCGP) Guidance

The RCGP recommends that all carers routinely receive an assessment from their GP in relation to their health and wellbeing. They provide a range of evidence based resources to help GPs and primary healthcare staff in their support of people with caring responsibilities.

The RCGP, in collaboration with NHS England and NHS Improving Quality, also regularly facilitates Carers Evidence Summits, which identify best practice examples of what is working well for carers across the UK, with topics including:

- Carers' break - health and wellbeing
- Carer support
- Dementia
- Eating disorders and substance abuse
- Education, information and signposting
- End of Life Care
- Identification and recognition
- Mental health
- Young carers

#### 4.1.3 Carers UK

A systematic review of interventions directly targeted at carers was undertaken to support local commissioning of services. The review (Victor, 2009) included those concerned with supporting carers to access services; those targeted at carers' physical health; interventions focused upon emotional and social support; education and training for carers; employment-related interventions; and carer breaks.

#### 4.1.4 The Royal College of Nursing (RCN)

The RCN provides a wealth of guidance, information and support for carers, those working with carers and those commissioning services to support carers. Assessment tools, strategies and information documents are available.

#### 4.1.5 National Institute for Health and Social Care Excellence (NICE) Guidance

NICE provides specific guidance identifying recommendations for carers including:

- ([CG185, 2014](#)) NICE recommends that carers of people with bipolar disorder are offered an assessment, provided by mental health services, of their own needs and discuss with them their strengths and views.

- ([CG178, 2014](#)) In their updated guidance on treating and managing psychosis and schizophrenia in adults, NICE recommends that carers' needs should be assessed to ensure they get the right level of support.
- ([CG42, 2012](#)) In their guidance for supporting people with dementia and their carers, NICE recommends that wherever possible and appropriate, agencies should work in an integrated way to maximise the benefit for people with dementia as well as their carers.

#### 4.1.6 Department of Health Guidance: School Nurse Programme

The Government provides evidence around what works locally in providing seamless support and local solutions to support the health and wellbeing of young carers.

#### 4.2 Local Evidence

Local evidence of effective support for carers has been developed through, service evaluations, reviews and public insight. This includes Knowsley's Carers Strategy Refocus 2015-2017

The strategy is written by Knowsley people for Knowsley people. It sets out the new priorities for carers in Knowsley identified through regular consultation and involvement with working groups and public events with carers, ex-carers and their representatives who have said what is important to them, and what they need to continue caring for their loved ones.

The strategy also evaluates the previous Carers Strategy (2011-2014), identifies how to build on this and clarifies priorities for the future.

### 5. CURRENT SERVICE PROVISION

There are a number of Carer specific services provided for Knowsley residents. All of the services described below are funded via pooled budget arrangements (between Knowsley Council and Clinical Commissioning Group) either through a contract, formal grant agreement or grant.

The services described are available to any carer who identifies themselves as a carer. There are no eligibility criteria or charges for any of the services.

All the services described are a mixture of preventative and low level wellbeing support.

#### **Knowsley Carers Centre:**

The Carers Centre provides a range of core activities for all adult carers aged 18 years and above who identify themselves as a carer (including carers of disabled children). They provide support such as information and advice,

signposting, case work, training events, support groups and other services that help carers continue in their caring role.

They also support carers by providing benefits advice, social and leisure activities, health promotion and a range of other activities for which funding is provided through other sources.

### **Knowsley Alzheimer's Society:**

The Alzheimer's Society supports adult carers of people with a diagnosis of dementia. They offer information and advice, signposting, one to one case work, peer group support and support groups.

### **Carers Support (for carers supporting people with a mental illness)**

Knowsley Carers Centre currently provide a specific carer service for those carers who are supporting people with a mental illness. They provide information and advice, signposting, one to one case work and support groups.

### **Young Carers Support:**

This is currently provided via Knowsley Youth Mutual and offers young carers and their families support and information in maintaining their health and wellbeing.

### **Carers Breaks**

In Knowsley we have an agreed definition for what a carers break means as agreed through the Knowsley Carers Strategy 2011-14.

#### Time for Me

A break from caring is different for each person and can change over time and circumstances.

It is time away from the physical, practical and emotional part of caring. This can be anything from 1 hour to several weeks to give time to rest, or a chance to experience new things.

A break can be any activity that gives time away from their caring responsibilities, in any location that they choose. This can be time for themselves, with the person they care for, with family or friends.

This definition covers much more than the traditional definition of respite care which is associated with services provided through the care management process.

**Kirkby and Prescott Caring Companions:**

Supports social clubs for carers, the cared for and former carers to meet socially and take part in leisure and social activities.

**Wellbeing Carers Services:**

These are small scale projects focused on specific activities that have been identified by carers as being positive in providing a break from caring or supporting their caring role.

- Holistic therapies.
- Therapeutic counselling
- Pamper sessions.
- Social and leisure activities
- Training carers as trainers and facilitators.
- Supporting carers community groups
- Carers Partnership Board Fund allocated to projects supporting carer breaks.
- Knowsley Carers Emergency Card

**6. CHALLENGES AND GAPS**

Carers provide a vital role in supporting people to remain in the home and live as independently as possible. Carers have a number of challenges that they have to overcome to maintain their own health and support those they care for. Supporting carers is vitally important to the Knowsley health and wellbeing system and wider community, but significant challenges exist in ensuring that carers continue to be effectively supported. However, before, looking at the challenges it is first important to recognise the strengths within Knowsley in respect to carers. The strengths are as follows;

- Carers bring their own strengths, skills and knowledge to each individual caring situation but also use those strengths to support other carers in sharing their experiences and knowledge. Word of mouth is a powerful tool that carers use to share information and access to services.
- The Knowsley Carers Strategy and Refocus was developed by carers for carers, with engagement and involvement integral throughout its development.
- There is a strong willingness amongst the residents of Knowsley:
  - To be a carer and care for people. There is strong resilience amongst individuals to support themselves to deal with the impact of caring.

- To engage with partners and influence policy direction and the design and development of local carers services.
- A strong community commitment and cohesion to supporting carers, particularly demonstrated via support groups such as Memory Lane, Caring Companions

### **Challenges**

There are a number of challenges that exist for carers and for services that currently support carers, which are detailed throughout this report.

The most significant challenges for meeting carers needs are;

- How to deal with the unprecedented reductions in public sector funding, particularly local authority budgets, which mean that difficult funding decisions have to be made about the provision of services including those for carers and for individuals with disabilities.
- The changing population and needs within the borough, which will result in an increase in the number of people requiring care and demand for services:
  - Increase in over 50 age group
  - Increase in dementia prevalence
  - Increase in survival rates amongst those with chronic diseases and complex care needs
- Potential decrease in people undertaking caring roles - While the number of people needing care is set to rise, social trends could, in the future, have an effect on the number of available carers. The growth in the number of lone parents, falls in birth rates, higher divorce rates, the increase in the numbers of people living alone and greater family mobility may all have an impact on the numbers of people available to assume a caring role. In addition, the growing number of women who are employed outside the home will have implications for the number of carers, since women have traditionally fulfilled the caring role.
- Cultural change, so that carers and individuals with caring needs become less reliant upon public sector support.
- **Impact of The Care Act (2014) on local authority**

Under the Care Act, local authorities will take on new functions. This is to make sure that people receive services that prevent their care needs from becoming more serious, or delay the impact of their needs.

People can get the information and advice they need to make good decisions about care and support and have a range of providers offering a choice of high quality, appropriate services.

Importantly, the Act strengthens the rights and recognition of carers in the social care system, including, for the first time giving carers a clear right to an assessment of their support needs and to receive funded services.

The change in carers' rights will have an impact on the way services are provided locally and a significant demand on local authorities resources to undertake timely assessments and provide appropriate support.

There is likely to be significant impact on local authorities in terms of how the needs of all carers are going to be met. However, the contribution of informal carers to the health and well-being of the population of Knowsley is hugely significant.

In addition, there are challenges in the following areas;

- To continue to identify adult and young carers and provide them with the information they need.
- Identifying unmet needs – Between Adult Social Care and the 3<sup>rd</sup> sector carers organisation we have contact with approximately 8000 carers. The challenge is to reach out to those carers who are not in touch with services or who are not even aware that they are carers.
- Keeping carers as informed as they wish in relation to the upcoming changes in relation to Transforming Adult Social Care.
- Ensuring that carers are as informed and involved as they wish in the commissioning, delivery and monitoring of appropriate carers support services.
- To have an understanding of the impact on carers lives as a result of changes to Social Care Transport and Charging policies.
- Welfare reform impact– Reforms to welfare are likely to continue to have a significant impact on carers, many of whom are already struggling financially because of their caring role. Carers UK have continually recommended that an assessment of impact on carers is undertaken.
- The Knowsley Carers Strategy Refocus recognises that young carers, young adult carers, working carers and male carers are under-represented in the uptake and use of carer services and support. The Refocus aims to address these gaps through commissioning relevant services.

## **7. SOURCES OF EVIDENCE AND INTELLIGENCE**

Care Quality Commission (CQC) (2014)

Carers Trust

Carers UK

Office for National Statistics, Census 2011 and 2014

Children's Society (2013), Hidden from View

Department of Health, Adult Social Care, Carers

Liverpool Public Health Observatory (2012) Children and Young People's Emotional Health and Wellbeing Needs Assessment: Merseyside

NHS Information Centre

Social Care Institute for Excellence [SCIE], Young Carers

The Royal College of General Practitioners