

PUBLIC HEALTH



Joint Strategic Needs Assessment (JSNA)

Unpaid Carers Needs Assessment I. Main document

East Riding of Yorkshire Council
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EAST RIDING
OF YORKSHIRE COUNCIL



**East Riding of Yorkshire Council, Joint Strategic Needs Assessment (JSNA)
Unpaid Carers Needs Assessment**

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East Riding of Yorkshire Council, Joint Strategic Needs Assessment (JSNA)

Unpaid Carers Needs Assessment

1. Introduction

1.1 Overview of the unpaid carers needs assessment

The unpaid carers needs assessment is the outcome of an in depth process designed to develop comprehensive understanding of unpaid care in the East Riding of Yorkshire (ERY) in order to draw conclusions and make appropriate recommendations to inform the development of the Carers Strategy for the East Riding. The needs assessment primarily focusses on adult carers, but does make reference to young carers as well.

The Joint Strategic Needs Assessment (JSNA) is a process built to establish a shared evidence based consensus on key local priorities to inform the development of a Health and Wellbeing Strategy for the ERY. Consultation events across key stakeholders to inform the JSNA process were held in late 2014. This highlighted a variety of themes and issues that impact on health and wellbeing. Prioritisation exercises identified a consensus of the four most important areas to focus on and further investigate, one of which was unpaid carers.

Unpaid carers are an invaluable asset within the communities of the ERY. They provide care voluntarily to assist the person they care for to remain independent, but often it is done without any recognition of their hard work nor of the sacrifices they have to make. Also, carers often know most about the person they care for, their health issues and how their care is co-ordinated and managed.

Therefore developing an East Riding carers strategy based on a comprehensive needs assessment is pivotal to improving outcomes for unpaid carers and the people they care for. The work has been conducted by Public Health, Adult Services and other key partners such as the Carers Advisory Group (CAG). This needs assessment takes into account a wide range of data sources, including the voices of local people from East Riding who are unpaid carers, to ensure their specific personal and often difficult experiences are recognised.

An understanding of unpaid carers needs has been developed through an extensive process which has included:

- Carrying out a literature overview of the national evidence base relating to unpaid carers.
- Quantitative analysis of the key information sources that is held on unpaid carers.
- Qualitative information from carers' stories and views of professionals.
- Numerous stakeholder meetings, which involved discussion and negotiation of what the key priorities are with multiple partners from both within ERY Council and external to the local authority.
- Reviewing each source of information and establishing key themes via presentations by the relevant stakeholder and then further discussion amongst all partners. This process highlighted repetition of issues across the sources of data, where dominant themes emerged, thereby reinforcing the more emotive views of local carers with the established evidence base from the literature and quantitative analysis.



1.2 Definition of a carer

This document uses the Carers Advisory Group's definition of a carer, taken from their 2017 publication "Being a carer, our stories"; the first paragraph of which is quoted below.

"A Carer is someone who spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has a mental health problem and those looking after elderly parents often with distressing ageing problems; some are multi-carers who care for more than one person with special or particular needs."

2. Aims and Objectives

The aim is to understand and explain carers support needs and present appropriate recommendations to inform the development of a new unpaid carers strategy for the East Riding of Yorkshire, via the following objectives;

- Gather intelligence, utilising a range of sources and methods as follows:
 - A literature review on unpaid carers
 - Quantitative information relating to carers
 - Survey of Adult Carers 2016-17
 - Carers stories
 - Stakeholder views
- Presentation and analysis of all sources of information to establish key themes, thereby ensuring triangulation across the data sources.
- Increase local knowledge of carers needs and raise awareness across stakeholders.
- Create recommendations informed by key findings for the development of the East Riding Carers Strategy.

3. Key Findings

In order to establish some consensus amongst stakeholders on the key findings from the needs assessment, a group exercise was co-ordinated with presentations from each section of the data from this needs assessment. The aim of the session was to identify key findings, facilitated through further discussion and to establish triangulation across the different methods of data collection.

From the needs assessment process, the following were highlighted as the key issues for East Riding Carers:

1. Identification and self-identification of carers
2. Accessible information and services
3. Lack of transport and rurality
4. The ageing population and the burden of ill health
5. Respite care
6. Carers being listened to
7. Training
8. Frustrations and social isolation



3.1 Identification and self-identification of carers

Many individuals who have a caring role do not recognise themselves as a carer, people usually care for each other within a relationship. However, when one person develops one or more long term conditions that requires additional support the balance of the relationship changes, with one person in the relationship providing care and support to the other without as much reciprocal support from within the relationship. People feel this is their duty as it is often a life partner, friend, neighbour, parent or relative. Therefore the feeling is that it is important just to get on with it, there is a culture around being seen to be able to cope as carers often have feelings of guilt and frustration around their role but feel it is wrong to express that. They have a tendency to cover up their own health problems and don't have time to prioritise their own health needs. They often pretend they are okay to protect the person they are caring for but have great anxiety about the future.

It was evident from a number of the information sources included that although there is much work going on to identify carers, there are still many who are not identified or registered as carers and therefore may not be accessing support they would benefit from. Section 5.2 estimates there to be 38,000 carers (providing 1 hour or more unpaid care) in East Riding in 2016, however there were only 3,100 carers registered with East Riding Carers Support Service in May 2017. Stakeholder information presented in section 8.5.2 explains *“People don't call themselves carers, so how do health and social care services identify them or encourage them to identify themselves as a carer? Some carers don't recognise that they do actually provide a form of care.”*

Recommendation: Raise awareness across the general public and professionals of caring, the carers role and the identification of carers. Promote a culture change to enable, empower and encourage carers using a strengths based approach. Promote awareness, raising it as everyone's responsibility to create a change of culture around the carers role, so that people feel able and empowered to seek support. Include the identification of unpaid carers and a full assessment of their needs as part of Social Prescribing initiatives.

3.2 Accessible information and services

There are a wide range of services designed for people with long term conditions and their carers, or that can be of benefit to them. However it is not always straightforward for people in this situation to find the right information to meet their needs.

The needs assessment showed that carers need one place to get information, a comprehensive directory of services would be useful as they feel it is not clear who to talk to about which services are available, how to access them and generally understanding the services. However, different people do gain information from different methods and different settings.

For some people a loved one being admitted to hospital can be the start of the journey and they need improved communications of what to expect and how to gain support as they will often be distressed, upset and confused themselves. It would help if all health professionals would adopt the “hello my name is” campaign as carers feel frustrated at not knowing who the professionals are.

Stakeholders feel we need to feed all the information together so that services are developed, promoted and accessed and also there should be more consistency of services across East Riding and continuity of care when people move in and out of services e.g. home to hospital or respite, including across geographical boundaries.



Section 5.14.5 states that the proportion of carers who indicate it easy to find information about services, is 69.4% (2016/17). This leaves 30.6% of carers who are finding it difficult to find information about relevant services. Relate this to the estimated number of unpaid carers in East Riding and there are potentially 11,000 people who are in this situation.

The carers stories in section 7.4.1 highlight the issue:

"I have tried to find some help/manual/users guide/instruction book. I have contacted and subscribed to a number of help societies, clubs, memory cafes etc. But, with the best will in the world, these short in the areas I am deficient in."

"I appreciate that my suggestion of a manual or user guide is fanciful but is there anything that might remotely somehow help?"

Recommendation: Map services across the whole system using an asset based approach to fill gaps and ensure consistent information is maintained in an identified directory. Build capacity of front line staff to identify and support carers in accessing services via healthy conversations including signposting where appropriate. This is being developed as part of the Social Prescribing model for East Yorkshire and provides an opportunity to ensure the appropriate information is accessible.

3.3 Lack of transport and rurality

Due to the rural nature of East Riding, access to transport to utilise services is important. There is some availability of community transport initiatives via the voluntary sector but this varies across ERY. There is difficulty because of the dispersed nature of services due to the geography, location of the hospitals and no centralisation.

Findings show that access to support is difficult for those living in rural isolation, aspects of daily living such shopping can also be a challenge, as well as the ability to travel to hospital. If the person being cared for then moves to a care home, this isn't always in the community where they previously lived, causing difficulty in visiting for friends and family, increasing the isolation of the care home resident.

Section 5.4 explains that over 500 registered carers live in rural areas classified as 'rural village' or 'rural hamlets and isolated dwellings', making up almost 17% of the total registered number. As noted previously, it is more likely that these areas (particularly the 3.5% living in the latter category) will be exposed to limited public transportation and issues associated with isolation.

Stakeholders at the Carers Rights Day, described in Section 8, highlighted that limited infrastructure in rural communities creates challenges for people living in those areas, including access to primary care, hospital, other support services and community activities. This isolation contributes to other factors impacting on physical and mental health and wellbeing

Recommendation: Support the development of community transport initiatives to ensure comprehensive coverage across ERY to enable carers and those they care for to access services. Ensure the promotion of community transport initiatives as part of the solution for carers receiving social prescribing support. Technology offers future opportunities for accessing services, e.g. via skype, telephone appointments. Improving connectivity between dispersed services to improve the journey of the person being cared for and the carer's experience.



3.4 The ageing population and the burden of ill health

It is clear that nationally and in the ERY people are living longer and needing to be cared-for for longer, as those being cared for become older, as do their carers. Whilst life expectancy is increasing, healthy life expectancy is not keeping pace and unfortunately becoming elderly is linked to the prevalence of long term health conditions. As carers become older, they are developing long term health conditions which also require identification, support and management.

Key findings highlight a range of concerns around this issue, the data quite clearly highlights the extent and prevalence of this burden of ill health in terms of the ageing population but without an associated link to healthy life expectancy. Coping as a carer can be challenging and the added impact of their own health issues adds to the burden. There is associated worry, concern and anxiety as carers are very aware of the inevitability of this situation.

This issue is quantified section 5.1.2. which describes a “typical carer” as aged 65, who report their own health conditions such as a long standing illness, a physical impairment or disability, or sight and hearing loss. If the carer is referred to a service such as the Health Trainers it will most likely be for stress and anxiety. The prevalent conditions of the cared for person are similar and include problems connected to ageing. There is a 7 out of 10 chance that the cared for person is living with more than one health related condition. The literature review (Section 4.2) also highlights the increasing longevity of the cared for and the ageing of carers which also needs to be addressed in terms of changing needs.

A carer’s voice from Section 7.4.7 which highlights many examples of concerns for the future encapsulates the circumstances of many: *“My health began to suffer as I was diagnosed with cancer which involved surgery and a year of chemotherapy and radiotherapy. I was still caring for my husband but on my bad days managed to get extra help. This was followed 5 years later with a knee replacement which I found difficult to manage both my treatment and care at the same time.”*

Recommendation: Promote self-care for carers and giving support for healthy lifestyle behaviours. Embedding Making Every Contact Count and opportunities to Assess, Link and Connect carers with appropriate Health and Wellbeing services via Social Prescribing can facilitate this.

3.5 Respite care

Respite care can range from organising care at home for a couple of hours through to going away with the cared for person on specialised package holidays. Cost, availability, quality, continuity of care and knowledge of respite services are all important in respite care provision.

This needs assessment has established that these particular aspects present carers with barriers to accessing respite. More specifically, carers sometimes find it expensive and not always available when needed. Providing the same support for a person in respite as they receive from the unpaid carer can be difficult because of the extensive knowledge and experience of the unpaid carer. When a carer and the cared-for have a poor experience of respite care they are unlikely to access it further, meaning the carer never has a break. The carer needs to be able to trust that the cared-for is being looked after to the same standard as the carer would, so that they can actually have a break and not worry, if not the carer receives no respite. Sometime the cared-for person has a lack of willingness to receive respite care and this can cause resentment.



The literature review highlighted in Section 4.2 respite care to be an unmet need of patients and carers.

One carer states (Section 7.4.3) “Not being able to put my wife in respite as she will not get the same level of care as she gets at home, despite the high prices they charge” another says “we do get respite, but it is not always when you need it, having to book ahead months in advance”.

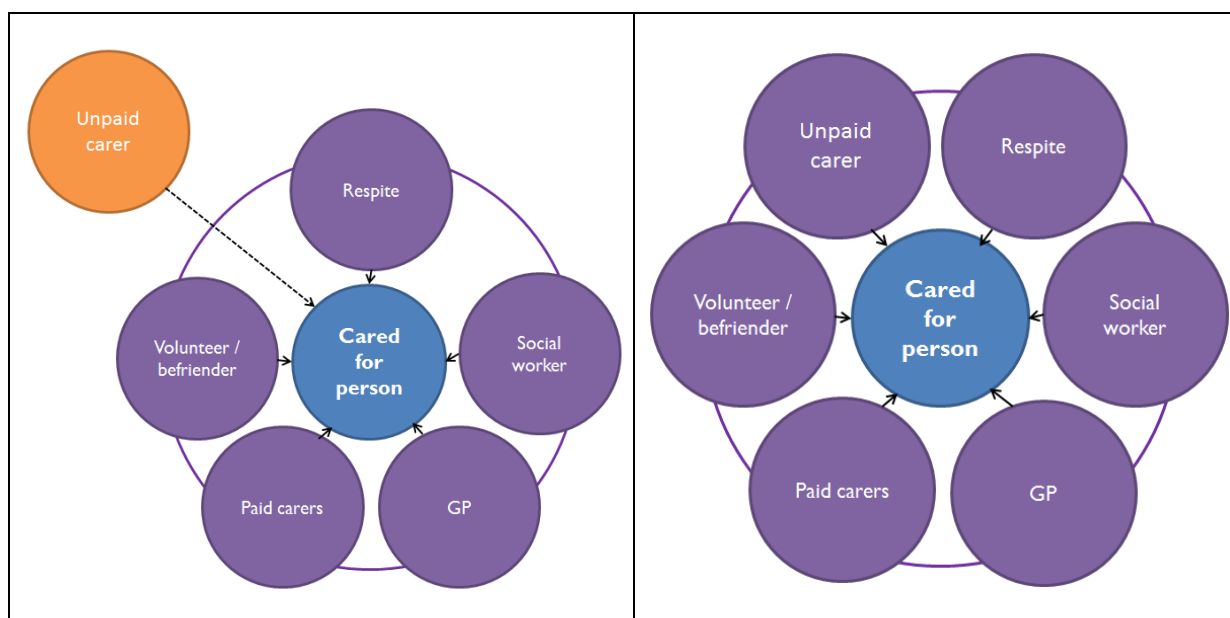
Recommendation: Map existing provision and further investigate gaps in provision to inform future development and improvement, e.g. sitting service, befriending, additional support for activities, residential respite. Improve continuity of care, from the unpaid carer to the professionals. Ensure that front line staff across Health and Social Care, including social prescribing link workers are aware of and promote respite care to carers, the person being cared for and their families.

3.6 Carers being listened to

There is a clear distinction between paid workers/professionals and unpaid carers, which can be a barrier in terms of holistic care for the cared for person. Carers may have no previous experience and learn as they go along, but are the key person for the cared for individual.

The evidence gathered highlighted that carers feel they need to be listened to by professionals, they are the person who spends the greatest amount of time with the person being cared for and are most familiar with them, particularly if they are a spouse or family member. A “whole” (holistic) approach (as shown in figure 1 below) with the person being cared for at the centre surrounded by everyone who is involved in their care would be the ideal.

Figure 1. Making the Unpaid Carer part of the care team. From outsider (illustration on left) to inclusive team member (illustration on right). Image source: ERY Public Health Intelligence team



Carers need to be recognised as part of the care team, involved in care planning with their experience and views included. This inclusivity would help to pass on information about the needs of the person being cared for from the unpaid carer to others involved in providing care, this could be health or social work professionals, paid carers, respite carers, or even a volunteer befriender. For



example a person with dementia can be labelled as having “challenging” behaviour but actually this behaviour is a response to the lack of continuity provided by the different people involved in their care.

The SACE survey (2016/17) as seen in Section 5.14.4, found that over a quarter of ERY unpaid carers had not been included or consulted in discussion about the person they care for. This issue is very emotive for carers as can be seen in Section 7.4.3 *“One would never for one minute consider withdrawing from their caring role. So sadly they continue to be used, abused and seldom listened to.”*

Recommendation: Increase inclusion of carers into the planning and provision of care so that they feel listened to and part of the care team.

3.7 Training

Carers can find themselves taking on the role of carer with no prior knowledge or experience of the health issues that the cared for person is experiencing. They learn as well as they can from experience and from other support that some may be able to access.

The sources of information within the need assessment highlighted that Carers expressed a need to receive training to be able to better fulfil their roles as unpaid carers. Informal and formal training both have their place and peer support and guidance from other unpaid carers is another useful component. The latter can be particularly beneficial for new carers and young carers in receiving peer support and those providing it to others.

Training specific to the condition of the person being cared for is needed, for example, if you are looking after someone who has had a stroke you need to understand the best way to look after somebody in terms of stroke rehabilitation. Another example would be dementia care, dementia being a particularly complex long term condition with specific challenges for unpaid carers. Understanding symptom management is important and looking after someone with multiple long term conditions can also be complex. Training provision needs to be flexible to take into account the demands on carers' time.

The literature review (section 4.2) highlights that training carers in rehabilitation in some conditions helps reduce carer burden and improve psycho-social outcomes.

Carers' stories (section 7.4.1) explain the circumstances of many carers: *“Having no previous experience or knowledge, her difficult behaviour has tested us”* and *“we never chose to be in this position and we certainly never trained for it, yet here we are”*.

Recommendation: Map existing provision and further investigate gaps in provision to inform future development and improvement of formal and informal training for carers. This should include peer support and condition specific information. All self-care training should include consideration for the involvement of carers as appropriate. Social prescribing provides an opportunity to link and connect carers with training opportunities and to even support them to build their own peer support groups, using asset based community development.



3.8 Frustrations and social isolation

This issue can be seen as the cumulative effect of many of the other key findings. Not self-identifying or being identified as a carer, struggling to find relevant information, living in rural situation without private transport, difficulty in receiving respite, not feeling listened to by professionals and feeling ill equipped or untrained for the role all impact on the overall experience of being a carer.

The findings show that carers frequently voice feelings of isolation and frustration because of their caring role. Their life may have changed greatly in a way they didn't expect or plan for when they took on a caring role for a loved one. They may feel duty and obligation to do this, but can experience grief at the loss of their previous life. The relationship with the person they now care for can have changed considerably, for example the relationship between carer and cared for can be very different to that of husband and wife. A carer can experience the loss of, for example, a career or rewarding working life that they may have had to give up. This can also have an impact on their financial situation. A caring role can also become very time consuming, leaving little time to maintain other social connections and activities and can also impact on relationships with the wider family. This in turn can decrease resilience and add to frustration. Carers may feel frustration about a situation, which they feel powerless to do anything about, yet feel guilt and shame that they may have come to resent the role of carer and the person they care for. Wishing for the death of the person they care for and themselves has been expressed.

The literature review highlights various contributors to this issue, in section 4.2; deprivation such as financial constraints and inadequate facilities and having to be eternally grateful. It also specifies; the loss of autonomy, challenge to self-identity and self-image.

In the section 7.3 on carers' stories the word frustration appeared in the statements of 64% of respondents. Several carers voice frustration with statutory services in section 7.4.3 “[I am} *slightly resentful that the authorities don't care, they just expect me to get on with it and save them money*”, and with the isolation experienced as a result of the changes in their lives “*My feelings towards my husband are now that of a carer and at times I feel like I am living with a child and not someone I used to be able to talk to and discuss day to day problems with.*” (Section 7.4.5)

Recommendations: The research demonstrates that the frustrations of being a carer are inevitable but identifying the cause of frustration can lessen suffering. Services and carers themselves need to recognise and accept frustrations exist, but often carers want to carry on with their caring role. However, carers need greater support to tolerate their situation, not necessarily change it. Much can be done to reduce the burden on carers and henceforth reduce some of these experiences. The previous recommendations under this needs assessment encompass the aspects of carers needs that need addressing to improve psychosocial outcomes for carers.



4. Carers literature review by ERY Public Health

4.1 Section introduction

This is a summary of a mini literature review performed from several databases of peer reviewed journals on the subject of carers, in October 2016. It became apparent that there is a dearth of good quality research on carers' physical wellbeing. Findings from some of those papers suggest that it is largely anxiety and associated symptoms that are a direct product of caring rather than physical ailments.

The main points from this mini review are itemised below. The full review and references are provided in Appendix I (in the separate appendix file). The review included a number of systematic reviews, a further mix of qualitative and quantitative evidence. A well-respected and validated measure of carers' responsibilities is also included. This measure and the items within it also provide some idea of the scope of the effects of being a carer.

4.2 Findings

- The Carers' Assessment of Difficulties Index is a validated measure for carers on five axis: Carer-dependent relationship, reactions to care-giving, physical demands of care-giving, restricted social life and poor family support (see Appendix 2).
- Caring has positive and negative effects, sometimes the positives can get ignored or overlooked and stress reduction models often miss the positive elements.
- Caring expectations have two distinct dimensions:
 - Visibility of care helps the cared for, know they are being cared for.
 - Presence of carers focuses on intrinsic qualities such as commitment and competence.
- Caring frustrations are:
 - Deprivation such as financial constraints and inadequate facilities and having to be eternally grateful.
 - Depreciation: loss of autonomy – challenge to self-identity and self-image which leads to hopelessness, weakness and meaninglessness.
- Caring frustration is inevitable but proper identification of the cause of dissatisfaction can lessen the suffering.
- Training carers in rehabilitation in some conditions helps reduce carer burden and improve psychosocial outcomes.
- Very little evaluation has been done on economic effectiveness.
- Unmet needs of patients and carers have been found to be:
 - Respite care.
 - More advice for time of death.
 - Lack of symptoms management education.
 - Continuity of care.
 - More advice about alternative medicines and euthanasia.
 - Spiritual needs.



- Hiding needs to protect others.
- Different conditions result in different levels and types of issues for patients and carers. Whilst there are common elements, bespoke interventions are ideal. For example, care givers with cancer or dementia report higher levels of burden and psychological distress compared to supporting someone with a chronic health condition or a frail older person.
- Those caring for a child with mental illness or multiple types of disability reported lowest subjective wellbeing across groups.
- Frequency of crisis and non-crisis cycles and predictability is a common source of strain for some conditions.
- Gender roles of carers need to be considered and common threads understood e.g. perceptions by the outside world of women carers is less lauded than male carers; male carers often feel the need to be more rational, task-based and block negative emotions.
- Increasing longevity of cared for and ageing of carers also needs to be addressed in terms of changing needs.
- Five key themes from caregiver experiences: stress of caregiving, negative impact on caregiver health, sharing the burden, worry about the future and caregiver coping strategies. In a 2008 study, 95% of carers said they hid the extent their health was affected in order to carry on their caring role and protect the cared for.
- Interesting findings show that low economic status and stressful life events led to people having greater compassion. This agrees with statistics in the US, showing that the poorest fifth of the USA donates the largest percentage of their income to charity.
- Young carers need someone who can help them tolerate their situation, not necessarily change it.
- Young carers need support even after clinical/professional sign off of the cared for.
- Children who are carers experience more bullying, are less happy at school, tend to have poorer educational outcomes when compared to children who aren't carers.
- Caring has some negative aspects for children but also positive ones such as nurturance, endurance and sympathy.
- Schools need to be flexible in accommodating young carers.
- Young carers should be involved in educating other young carers.



5. Quantitative information

5.1 Section introduction

5.1.1 Section aims

This section aims to quantify what is currently known about unpaid carers in East Riding of Yorkshire and primarily utilises three key sources of information:

1. The 2011 Census (based on 37,000 ERY carers providing 1+ hours of unpaid care).
2. The ERY Carers Support Service register of carers (based on 3,100+ ERY carers in May 2017 and also a database from August 2017 with more detailed information about registered carers).
3. The 2016/17 Survey of Adult Carers in England (SACE) database (based on 582 ERY carers, registered with ERY Carers Support Service).

The 2011 Census provided the basis for a large portion of the information, but where possible, information from the more recent sources (from points 2 and 3 above) will attempt to provide a more contemporary overview of unpaid carers in ERY.

5.1.2 Who is a typical carer in ERY?

The paragraph below paints a picture of the average ERY carer from the information obtained in the quantitative information of this section. However, this only summarises information about the carers (that are generally) known to services, the profile of the unidentified carer could be very much different altogether.

An ERY carer is most likely to be female, an average age of 65, caring for someone else of a not dissimilar age (70 years old on average). They are more likely to be economically active if providing fewer hours of care but not economically active if providing 50+ hours of care.

They are most likely to live in the most deprived areas of ERY with a higher rate per population living in areas classified as rural. If they live in the most deprived areas they are more likely to be in poorer health.

Carers report health conditions such as a long standing illness, a physical impairment or disability, or sight and hearing loss. If the carers is referred to a service such as the Health Trainers it will most likely be for stress and anxiety.

The most prevalent primary support needs for the person they care for includes 'Physical Support: Personal Care Support', followed by 'Mental Health Support'. The prevalent conditions of the cared for person include: 'A physical disability', 'Long-standing illness' and 'Problems connected to ageing'. There is a 7 out of 10 chance that the cared for person is living with more than one health related condition.



5.2 Numbers of unpaid carers in ERY

Key points in this section:

- Significantly higher percent of carers in the ERY population, than the national average (2011)
- Estimated to be over 38,000 carers in ERY in 2016 (providing 1+ hours per week)
- Only 3,100 carers registered with Carers Support Service, suggesting potentially 35,000 not in contact and presents the problem of carer identification and self-identification.
- Higher rates of carers within Bridlington area, South East Holderness and North Holderness wards.

5.2.1 ERY overall (2011 census and estimates for 2016)

The count of ERY unpaid carers in 2011 is provided in table 5.2.1, displaying the number of hours of care given and also the respective proportion by each category for ERY and England. The 2011 census reports that there were 37,368 ERY carers providing 1+ hours of unpaid care per week, 13,000 providing 20+ hours and 8,595 providing 50+ hours.

In contrast, the previous 2001 census reported there were 32,765 ERY residents providing 1+ hours unpaid care per week, with 6,444 providing 50+ hours. Therefore, between 2001 and 2011 the number of persons providing unpaid care rose by 14% (for 1+ hours) and 33% (for 50+ hours).

Table 5.2.1 Count of ERY carers providing unpaid care by number of hours. Each category also shown as a percent of total population for ERY and England. 2011. Source: NOMIS

Category	ERY: count of individuals	ERY: category as % of total	England: category as % of total
Total population	334,179	100%	100%
Provides no unpaid care	296,811	88.8%	89.8%
Provides unpaid care	37,368	11.2%	10.2%
Provides 1 to 19 hours unpaid care a week	24,355	7.3%	6.5%
Provides 20 to 49 unpaid care a week	4,418	1.3%	1.4%
Provides 50 or more hours unpaid care a week	8,595	2.6%	2.4%
Total (carers hours categories)	37,368	11.2%	10.2%

The table shows that ERY carers made up 11.2% of the total ERY population, 1% more than the England average and despite this difference appearing to be a small it is a statistically significant difference. Those ERY residents providing 50+ hours of unpaid care make up 2.6% of the total population, also significantly higher than England (2.4%). A higher proportion of carers in ERY compared to England was not unexpected, given that in 2011 the East Riding had a higher percentage of older people living within the population than the England average (as it still does today).

It is extremely difficult to know precisely how many ERY carers there are in the years since the last census. The census is the only comprehensive source of small area data about the provision of unpaid care (ONS, 2012) and the next one is not expected until 2021. However, it is possible to make an approximation by taking the prevalence of carers in each 2011 census age group and applying it to the latest mid-year estimate (in this case 2016). Other sources of information, such as [POPPI](#), use a similar methodology to estimate the number of unpaid carers aged 65+ in the future.



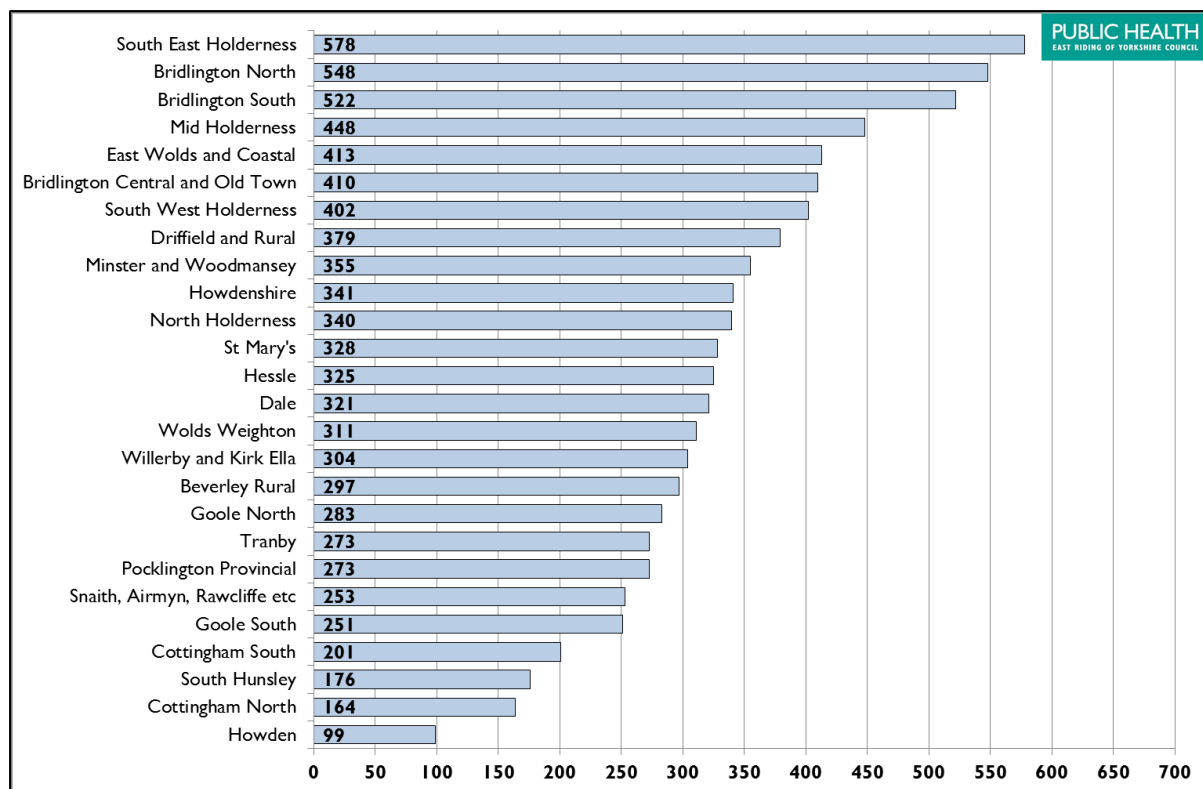
The results based on this methodology suggests in 2016 there were over 38,200 ERY carers providing 1+ hour of care and in excess of 9,100 providing 50+ hours. In contrast, during May 2017 there were approximately 3,100 unpaid carers registered with the East Riding Carers Support Service. Therefore, this would suggest there might be 35,000 carers providing 1+ hour unpaid care and 6,000 carers providing 50+ hours of unpaid care, who are not in contact with local authority carer related services. The identification and self-identification of carers has been identified as a major issue within this document. The mid-year estimate for 2016 was used, as opposed to the ONS population projection for 2017, as it was perceived that the former would be the more accurate of the two. The last population projections for 2017 were produced by ONS based on 2014 data and it was therefore felt that the 2016 mid-year estimate was more suitable.

5.2.2 ERY wards (2011 census)

Within the wards of ERY, the number of unpaid carers providing 1+ hours of unpaid care in 2011 ranged from 508 in Howden to over 1,900 in South East Holderness; for 50+ hours it was the same wards at each end of the scale (99 and 578 carers respectively). Chart 5.2.2 below displays the count of carers (providing 50+ hours of unpaid care) within each individual ward. The appendix shows a similar chart (chart A3.1) for the number of carers providing 1+ hours of unpaid care. A summary table of the ward numbers illustrated in the charts can also be found in the appendix (table A3.3), whilst table A3.4 displays the numbers of carers in each ward providing unpaid care by other categories of hours (i.e. 1+ hours, 1-19 hours, 20-49 hours and 50+ hours).

Table 5.2.2 Count of unpaid carers within each ERY ward. 50 hours or more unpaid care per week, 2011.

Source: PHE Local Health

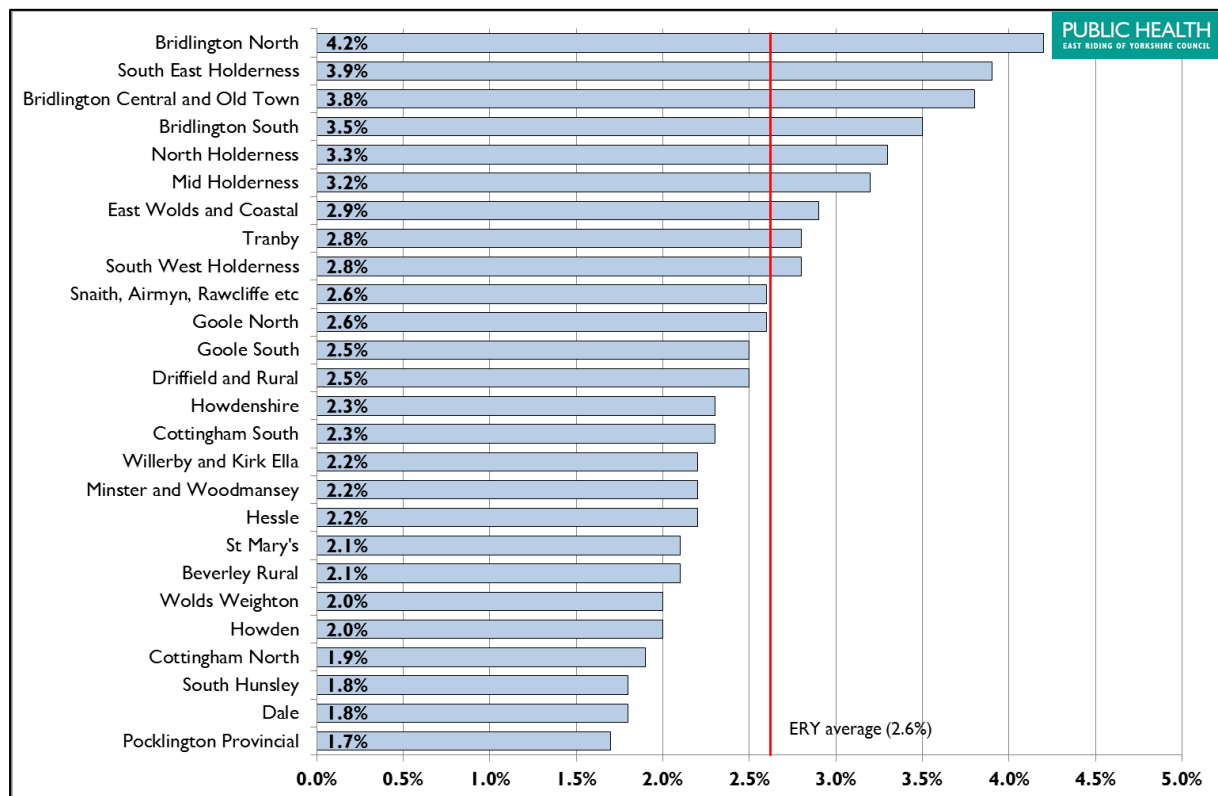


Rather than simply counting the *numbers* of carers by ward (with larger numbers having a tendency to congregate in the more population dense urban areas) it is useful to examine which wards have a



higher percentage of carers within their own population. The prevalence of unpaid carers providing 1+ hours ranged from 8.9% in Goole South to 14.1% in Bridlington North (illustrated by chart A3.2 in the appendix). For 50+ hours of unpaid care (chart 5.2.3 below) Pocklington Provincial is shown to have had the lowest proportion (1.7%) and Bridlington North the highest (4.2%). For the latter ward, this indicates that 1 in 25 persons within the Bridlington North population, provided 50+ hours of unpaid care.

Chart 5.2.3 Number of unpaid carers as % of total ward population (all ages). 50 hours or more unpaid care per week, 2011. ERY wards compared to ERY average. Source: PHE Local Health



Further calculation revealed there were six wards with a significantly higher proportion of carers providing 50+ hours of unpaid care, compared to the ERY average; looking back to chart 5.2.3 these were Mid Holderness (3.2%) through to Bridlington North (4.2%). It is apparent that it is the more deprived wards of ERY (with the exception of Goole South) which are amongst those with the significantly higher proportions of unpaid carers providing 50+ hours. For 1+ hours of unpaid care per week, there appears to be no clear pattern regarding deprivation about the type of wards which have the highest proportions. There is a mixture of deprived and less deprived wards which have higher proportions than the ERY average. A map showing the geographic location of the wards of ERY is also available in the appendix (map A3.5).

5.2.3 ERY wards (carers registered with the East Riding Carers Support Service)

A snapshot of the May 2017 East Riding Carers Support Service database, found that there were 3,166 unpaid carers registered. Table 5.2.4 displays the ERY wards where these carers live, ranked in descending order by count of the number of carers living there. Of this cohort of registered carers, South East Holderness had the highest number (n=194) followed by St. Mary's (n=192); the top six wards represent approximately a third of the total registered carer population.

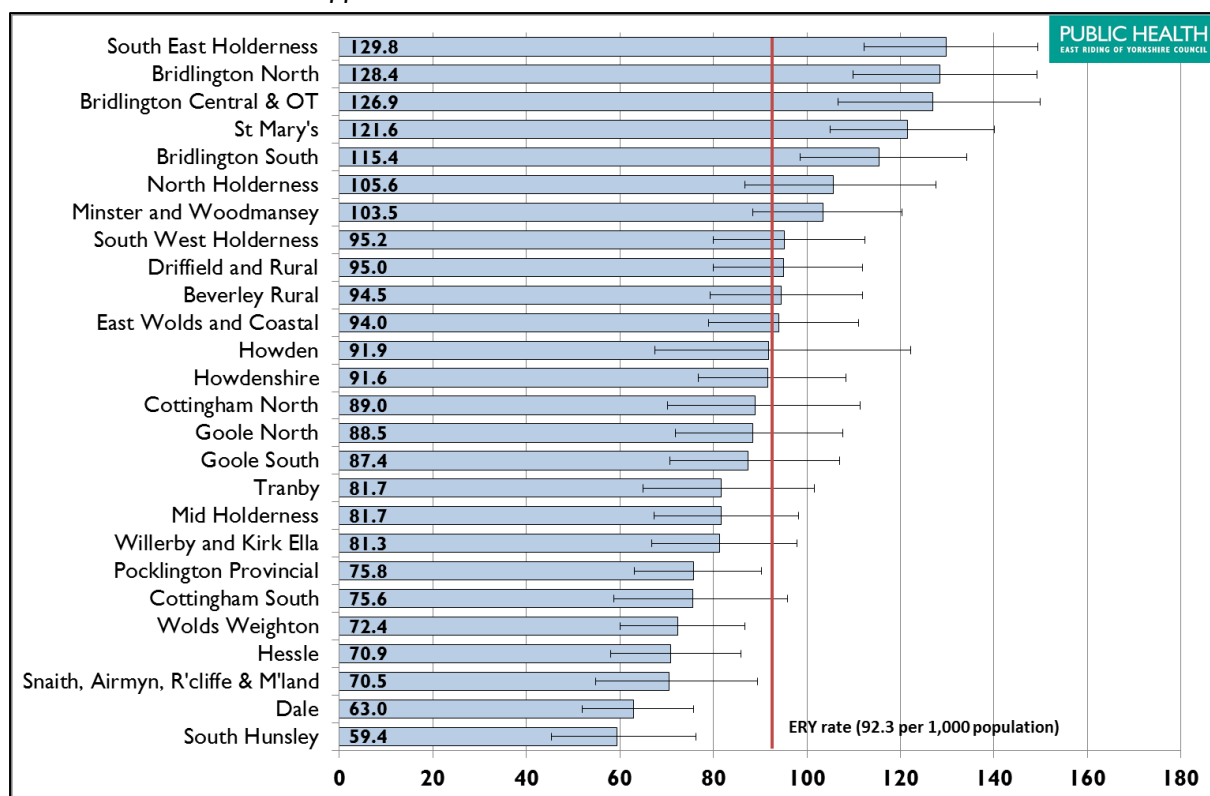


Table 5.2.4 Number of registered carers (with ERY Carers support service) by ward and respective % of total ERY registered carer population. May 2017. Source: ERY Carers Support Service

Ward Name	Count of carers	Percent	Ward Name (continued)	Count of carers	Percent
South East Holderness	194	6.1%	Dale	112	3.5%
St Mary's	192	6.1%	Willerby and Kirk Ella	110	3.5%
Bridlington North	170	5.4%	North Holderness	108	3.4%
Bridlington South	169	5.3%	Hessle	105	3.3%
Minster and Woodmansey	169	5.3%	Goole North	99	3.1%
Driffeld and Rural	143	4.5%	Goole South	94	3.0%
Bridlington Central & Old Town	139	4.4%	Tranby	81	2.6%
South West Holderness	139	4.4%	Cottingham North	76	2.4%
East Wolds and Coastal	137	4.3%	Cottingham South	68	2.1%
Beverley Rural	135	4.3%	Snaith, Airmyn, Rawcliffe & Marshland	68	2.1%
Howdenshire	135	4.3%	South Hunsley	61	1.9%
Pocklington Provincial	125	3.9%	Howden	47	1.5%
Wolds Weighton	119	3.8%	(Outside of ERY LA boundary)	58	1.8%
Mid Holderness	113	3.6%	Total	3,166	100%

As noted in section 5.2.2, it's likely that most carers may naturally reside in the more populated urban areas of ERY, such as Withernsea (South East Holderness), Beverley (St. Marys, Minster and Woodmansey), Bridlington and Driffeld (Driffeld and Rural). Therefore, it is useful to look at the rate per population of registered carers within ERY wards. Chart 5.2.5 displays the crude rates per 10,000 population for each ward, finding that the results are not vastly dissimilar from table 5.2.4 in terms of ward order.

Chart 5.2.5 Registered carers with ERY Carers support service, crude rate per 10,000 ward population, May 2017. Source: ERY Carers Support Service



Five wards have a significantly higher rate than the ERY rate (92.3 per 10,000) of registered carers; the three Bridlington wards, South East Holderness and St. Marys. The wards with significantly lower rates are South Hunsley, Dale, Hessle and Wolds Weighton. South East Holderness had the highest rate of registered carers in 2017 (129.7 per 10,000), over twice that of the ward with the lowest rate (South Hunsley).

The wards with the higher rates of carers in May 2017, are similar (with one or two exceptions) to those that had the highest proportions in the 2011 census. These are: the three Bridlington Wards, South East Holderness and North Holderness. There is another similarity when comparing the census and the registered carers database. Both appear to show a higher rate of registered carers residing within the more deprived wards of ERY and a lower rate within the least deprived wards. Deprivation is analysed in more detail in the next section.

Table A3.3 in the appendix also displays the difference in the number of carers identified from the census providing 50+ hours unpaid care by ward and those registered with the East Riding Carer Support Service in May 2017. Whilst this arguably cannot be considered a precise comparison between the two sources (due to the difference in time periods and the number of hours of care in the latter source is not specified), it might help identify in which areas carers are not identified or self-identified. In South East Holderness, the census stated there were 578 carers providing 50+ hours unpaid care but only 194 carers were registered in May 2017, equating to a difference of 384. In this instance, it would seem two thirds of carers in South East Holderness are not registered with the Carers Support Service. In Bridlington North, the difference in number was 170 and similarly in Bridlington South it was 169. Please refer to table A3.3 in the appendix file for all ERY ward numbers.

5.3 Carers living in areas of deprivation

Key point in this section:

- *A significantly high proportion of carers live in the most deprived communities of ERY*

In the last section there was a suggestion that a higher proportion of carers lived in the more deprived wards of ERY. However, whilst using wards to illustrate deprivation is convenient and easier to understand (as people recognise wards as geographic areas) it can be misleading. Not *all* of a ward will necessarily be deprived nor, on the other hand, will all of a ward be particularly affluent. Instead, local deprivation quintiles are calculated by splitting the 210 ERY Lower Layer Super Output Areas (LSOA) into fifths by their overall Index of Multiple Deprivation (IMD) 2015 deprivation score.

In 2011, no clear pattern of deprivation emerges for those providing 1+ hours of care, however for those caring 50+ hours per week it is much more apparent. Approximately 27% of carers (providing 50+ hours) live in the most deprived ERY local quintile, which has a significantly larger proportion than any of the other quintiles. Half of unpaid carers (50+ hours) live within the two most deprived ERY local quintiles, compared to 15% living in the least deprived quintile, as summarised in table 5.3.1 below. Chart A3.6 in the appendix displays the proportions of ERY carers (for both 1+ and 50+ hours) residing in each deprivation band in 2011.



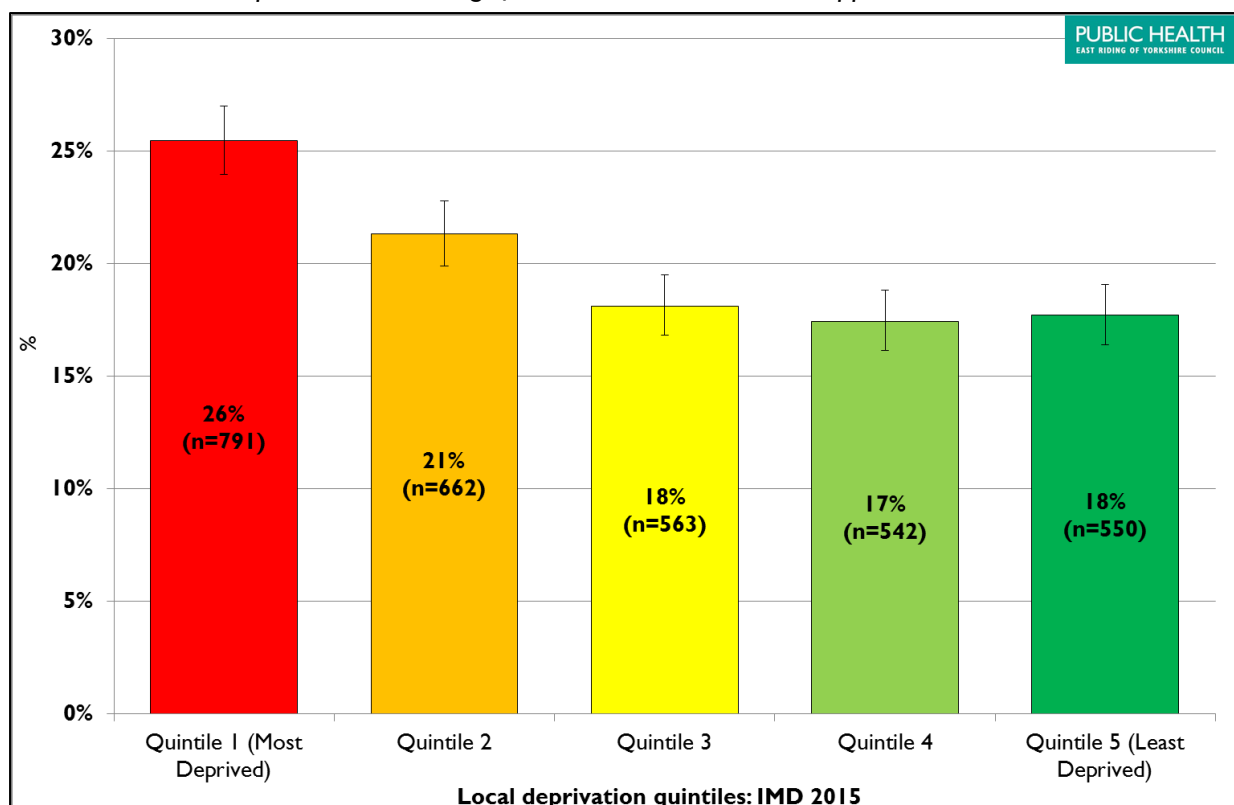
The May 2017 dataset of registered carers from the ERY Carers Support Service allows for a comparison of more recent information; the split by deprivation band is also shown in table 5.3.1. The pattern of carers living in a particular deprivation quintile is similar to that of 2011. The table finds over a quarter of the registered carers with ERY Carers Support Service were resident within the most deprived ERY neighbourhoods (based on local IMD 2015 quintiles) and almost 50% of registered carers (1,500 in number) live in the two most deprived quintiles. At the opposite end, 18% of registered carers lived within the least deprived areas of ERY. Chart 5.3.2 displays the counts and proportions of registered carers in each deprivation quintile.

Table 5.3.1 Proportion of ERY unpaid carers living in each local deprivation band (based on IMD 2015). Census 2011. and ERY Carers Support Service database, May 2017. Source: NOMIS and ERY Carers Support Service

Data Source	Band 1 (most deprived)	2	3	4	Band 5 (least deprived)
Census, 2011 (50+ hours of unpaid care only)*	27%	23%	20%	16%	15%
ERY Carers support service, May 2017	26%	21%	18%	17%	18%

* numbers do not add up to exactly 100% due to rounding

Chart 5.3.2 Where carers live (registered ERY Carers support service), May 2017. Postcode of carer converted to local deprivation quintiles (IMD 2015). Number & percent of carers shown in each quintile. Colours used do not represent statistical significance. Source: ERY Carers support service

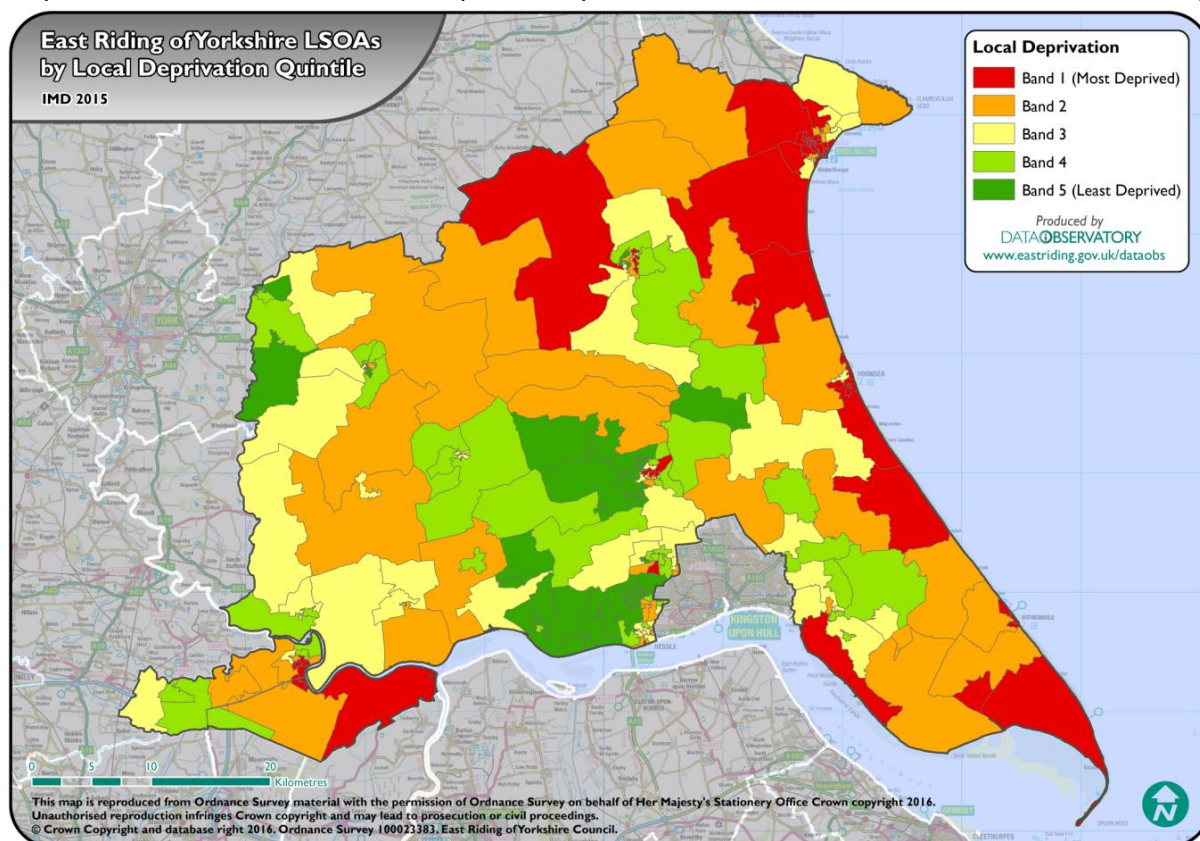


The dispersion of the different local deprivation quintiles around the ERY local authority boundary is visible in map 5.3.3. However, it should be noted that there won't necessarily be significant amounts of carers living in *all* of the areas highlighted; the maps simply shows which areas fall within each local deprivation quintile. This map should also not be confused with other deprivation maps of the ERY,



which may use national deprivation quintiles or deciles and will therefore present different shadings of deprivation in different areas of the ERY.

Map 5.3.3 Location of ERY local deprivation quintiles, IMD 2015. Source: ERY Data Observatory



5.4 Carers living in urban and rural areas

Key point in this section:

- A higher rate of carers live in areas classified as rural.
- In 2011 over 1,700 carers providing 1+ hour of unpaid care lived in areas classified as 'rural hamlet and isolated dwellings', 340 of whom provided 50+ hours of unpaid care.
- However in May 2017, there were only 109 carers registered with East Riding Carers Support Service who lived in areas classed as 'rural hamlet and isolated dwellings'.

This section provides the numbers and rates of carers living within the urban and rural areas of the ERY. The only urban category used in this section is called 'urban city and town', which are urban settlements with a population of 10,000 or more. There are three rural categories; ranging from the more densely populated 'rural town and fringe', then 'rural village' and finally the more sparsely populated 'rural hamlet and isolated dwellings'.

The urban and rural classifications can potentially be misleading as they are designed to cover census output areas, which require a certain size of population. Some 'urban' areas can include open areas



of countryside (including dwellings located there) and, in contrast, areas classified as ‘rural’ do not necessarily mean that they are exclusively open countryside.

If we were simply to divide the unpaid carer population into percentages by their urban and rural categories, we would find that approximately 55% live in urban areas (for both 1+ hours and 50+ hours). However (as previously noted) as more people live in urban areas anyway we might expect the majority of unpaid carers to live in urban areas too. Table 5.4.1 below shows that by count, there are indeed a larger number of unpaid carers in the urban areas.

Table 5.4.1 ERY unpaid carers residence: count and crude rate per 1,000 population by urban/rural category. Comparison with England crude rate per 1,000 population. Census 2011. Source: NOMIS*

Rural/Urban category	1+ hours of unpaid care			50+ hours of unpaid care		
	ERY count	ERY crude rate per 1,000 population	England crude rate per 1,000 population	ERY count	ERY crude rate per 1,000 population	England crude rate per 1,000 population
Urban city and town (urban total)	20,345	109	102	4,747	25	24
Rural town and fringe	9,032	111	112	2,100	26	25
Rural village	6,269	125	119	1,409	28	23
Rural hamlet and isolated dwellings	1,722	112	119	339	22	21
Rural (total)	17,023	116	116	3,848	26	24
Total	37,368	112	102	8,595	26	24

* the count of carers providing 50+ hours unpaid care is also included within the total of 1+ hours unpaid care, so should not be added together

Table 5.4.1 also divides the unpaid carer population (1+ hours and 50+ hours) by the more detailed urban and rural categories in which their neighbourhood falls within. The table provides the count of carers in each category and also the corresponding crude rate per 1,000 population. For both the 1+ hours and 50+ hours of unpaid care categories, it was the rural areas which had the higher rate of unpaid carers living there, compared to urban areas.

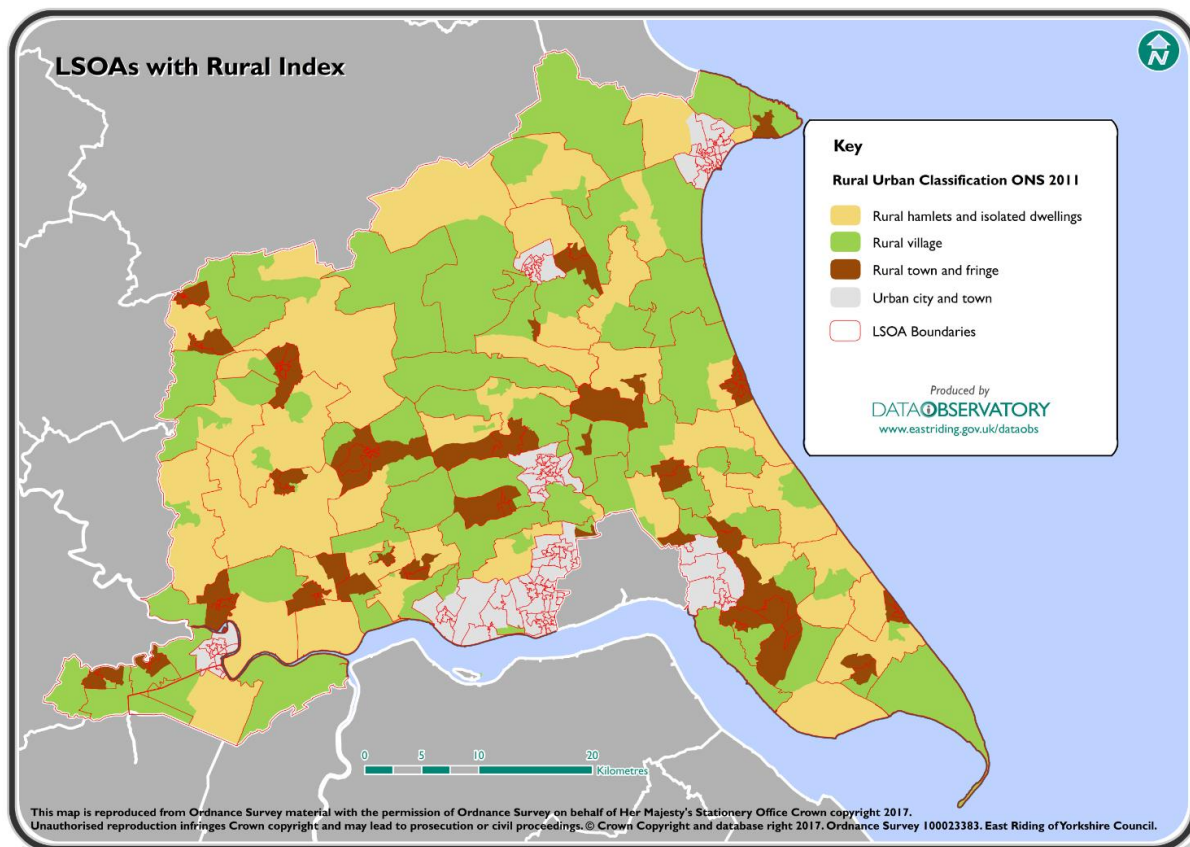
By count of population it is the ‘rural town and fringe’ category that has highest number of unpaid carers in rural areas, but it is the ‘rural village’ category that has the highest rate of unpaid carers per 1,000 population. It has already been established that ERY has a significantly higher proportion of unpaid carers than the England average, but for 50+ hours of unpaid care, every single urban/rural category has a higher rate per population in the ERY compared to England.

In 2011, there were over 1,700 unpaid carers living in the ‘rural hamlet and isolated dwellings’ category, a number of these areas are likely to include some of the most remote and isolated areas of the East Riding.

Map 5.4.2 on the next page provides a visual representation of the different urban and rural areas within the ERY boundary. Please note the maps simply highlights where the categories are situated and does not indicate any prevalence of unpaid carers.



Map 5.4.2 Urban and rural areas within ERY, 2011. Source: ERY Data Observatory



The ERY Carers Support Service database provides a more up to date analysis of urban and rural classification of unpaid carers, table 5.4.3 presents the findings from the May 2017 dataset. As found with the 2011 census, simply dividing this sample into percentages by category finds that most (58%) of the registered unpaid carers were living in 'urban city and town' category, with the remaining residing in rural areas. To remove the confounding factor of more people generally living in urban areas, the table has also produced crude rates per 10,000 population by each category.

Table 5.4.3 Registered carers by urban/rural classification: count*, % of total registered carer population and crude rate per 10,000 population. May 2017. Source: ERY Carers Support Service

Category	Count	% of total carer population in database	ONS mid-year 2015 population	Rate per 10,000 population
Urban city and town (urban total)	1,794	57.7%	189,478	95
Rural town and fringe	789	25.4%	81,983	96
Rural village	416	13.4%	49,920	83
Rural hamlets and isolated dwellings	109	3.5%	15,304	71
Rural total	1,314	42.3%	147,207	89
Total	3,108	100.00%	336,685	92

*some of the 3,166 (total carers, May 2017) postcodes are outside of the ERY boundary and so are not included in the table above.

In 2011, the rate per 1,000 population of carers living in all rural areas was higher than those in urban areas, but in the May 2017 database this was not the case. The rate of registered carers living in rural areas was 89 per 10,000 population compared with 95 per 10,000 in urban areas. The



individual category with the highest rate of registered carers per 10,000 population was 'rural town and fringe'.

Over 500 registered carers live in rural areas classified as 'rural village' or 'rural hamlets and isolated dwellings', making up almost 17% of the total registered number. As noted previously, it is more likely that these areas (particularly the 3.5% living in the latter category) will be exposed to limited public transportation and issues associated with isolation, compared to other areas of the East Riding.

As already mentioned in this section, in 2011 there were in excess of 1,700 carers (providing 50+ hours care) living in areas categorised as 'rural village' or 'rural hamlets and isolated dwellings'. This is 1,200 more than the number actually registered in these areas, as noted in the paragraph above. In the least densely populated category of 'rural hamlets and isolated dwellings' category alone, there were over 330 carers (50+ hours) identified in the 2011 census, but only 109 registered in May 2017.

5.5 Other characteristics (gender, ethnicity, economic status)

Key points in this section:

- A significantly higher proportion of women provide unpaid care than men
- 45% of carers providing 1+ hour of unpaid carer are economically inactive, this rises to 72% for those providing 50+ hours (2011)
- Out of those carers providing 50+ hours per week, over 2,200 were still in employment (2011)

5.5.1 Gender of unpaid carers

In the ERY, a significantly higher proportion of women provide unpaid care than men. For both 1+ and 50+ hours per week of unpaid care, the proportions were 58% for females and 42% for males. In all of the individual census age groups, females had the higher proportion compared to males.

The overall ERY gender proportions were the same as the England average for 1+ hours but for 50+ hours of unpaid care, England had a higher proportion of women carers (60%) than ERY (58%). The proportions by gender were distributed differently within individual the age groups, when comparing ERY and England. Please see tables A3.7 and A3.8 in the appendix which display the different gender proportions by age group, for ERY and England.

The ERY Carers Support Service (August 2017) database also found significantly larger amounts of female carers than males, reporting 65% of carers as females and 35% as males.

5.5.2 Ethnicity of the carer

The majority (99%) of ERY carers who provided one hour or more care per week in 2011, stated their ethnic group to be 'white'. This is generally the same proportion as found in all of the nearest 15 CIPFA neighbours to ERY, with individual values of these local authorities varying between 94% and 99%. In comparison, the England average had a lower percentage of the population classified as



‘white’, at 89%. Chart A3.9 in the appendix displays different ethnic groups providing care, as a proportion of all carers. In contrast to ERY and its nearest CIPFA neighbours, the ethnic diversity of carers within the England as a whole is much more varied.

However despite these statistics, consideration must still be made for carers of all ethnic backgrounds within the East Riding. In 2011 there were almost 350 ERY carers with an ethnic group other than ‘white’, further detail is displayed in table 5.5.1.

Table 5.5.1 Number of unpaid carers in ERY by ethnic group. Census 2011. Source: NOMIS

All categories: Ethnic group	White: Total	Mixed/multiple ethnic group: Total	Asian/Asian British: Total	Black/African/Caribbean/ Black British: Total	Other ethnic group: Total
37,368	37,020	119	173	27	29

5.5.3 Economic status of the carer

Unpaid care should not be considered ‘free’. If a carer is not able to be part of the labour market because of their caring commitments, then they forgo the opportunity to provide an income for themselves. A lack of income naturally exposes an individual to a wide variety of hardships and unpaid carers still absorb costs in terms of time and energy. The financial implications of caring for somebody are particularly acute when the carer has to give up work to continue the caring role and survive on the carers allowance of £62.70 per week (2017/18). In an attempt to make ends meet, Carers UK (2017) found that carers had to cut back expenditure on leisure activities, seeing family and friends and even food and heating. Coping mechanisms included using savings, spending on credit cards and organising bank overdrafts; as a result a fifth of carers revealed they were (or had been) in debt from caring responsibilities. Some carers may not have to give up work completely but instead accept a less qualified vocation, sacrificing the recognition they might normally deserve, e.g. achieving promotion, pay rises and overall career development. The demands of caring can cause tiredness, lateness and stress which all impact on the carers working life.

This section examines economic activity and inactivity of carers living in ERY, with a comparison against the England average. There is also analysis of the proportion of economically inactive carers living within the wards of ERY.

Nationally, Carers UK (2017) reported that 37% of carers responding to the 2017 Carers UK survey were in paid work. It also reported that 25% of carers providing 50+ hours per week, were in some form of paid work. For more local information relating to the East Riding, the 2011 census has to be consulted. The census divided economic activity into the following sections:

- Economically active: in employment, unemployed.
- Economically inactive: retired, student, looking after home/family, long-term sick/disabled.

Table 5.5.2 reveals 44.6% of ERY carers providing 1+ hour of unpaid care were economically inactive and for 50+ hours this figure rose to 71.9%. In both cases, the ERY proportions were significantly higher than the equivalent proportions for England.

Whilst it might be expected that there is a higher proportion of economically inactive carers providing 50+ hours care, the table shows that 26% (n=2,200+) were still in employment.



Table 5.5.2 Number and percent of unpaid carers who are economically inactive/inactive. Census 2011.

Source: NOMIS

Economic activity status		1+ hours			50+ hours		
		Number	Percent		Number	Percent	
		ERY	ERY	England	ERY	ERY	England
Economically active	In employment	19,375	52.6%	54.2%	2,228	26.0%	28.2%
	Unemployed	1,011	2.7%	3.7%	180	2.1%	2.8%
	Total	20,386	55.4%	57.9%	2,408	28.1%	31.0%
Economically inactive	Retired	12,190	33.1%	26.6%	4,344	50.8%	40.6%
	Student	476	1.3%	2.0%	58	0.7%	1.1%
	Looking after home/family	2,155	5.9%	7.9%	1,057	12.4%	17.3%
	Long-term sick/disabled	1,046	2.8%	3.7%	476	5.6%	6.7%
	Other	570	1.5%	2.0%	212	2.5%	3.2%
	Total	16,437	44.6%	42.1%	6,147	71.9%	69.0%
Total carers		36,823	100.0%	100.0%	8,555	100.0%	100.0%

Charts A3.10 and A.11 in the appendix display the percent of economically inactive carers by ERY ward for 1+ hours and 50+ hours of unpaid care respectively.

For 1+ hour of unpaid care, five wards had proportions of economic inactivity that was significantly higher than the ERY average. These included some of the East Ridings most deprived wards including two in Bridlington and South East Holderness. Bridlington North was the ERY ward with the highest percent (60.5%) in contrast to Hessle which had the lowest (38.1%).

Three wards were significantly higher than the ERY average for economically inactive carers providing 50+ hours unpaid care. They included the particularly deprived ERY wards of Bridlington Central and Old Town and South East Holderness. Bridlington North had the highest proportion (83.5%) of economically inactive carers, in contrast with Dale at the opposite end of the chart (61.1%).

More recent information about the economic status of the carer is summarised in section 6.5, with data obtained from the 2016/17 SACE survey.



5.8 The age of ERY unpaid carers

Key points in this section:

- The average age (median) of a registered East Riding carers is 65 years.
- In 2011, carers providing 50+ hours of care were predominantly 65 years old and over.
- ERY has a significantly higher proportion of older carers than the England average.
- Older carers are projected to increase in number as the population gets older.
- 1,466 carers aged 65+ years registered with the Carers Support Service, but estimated to be an additional 3,000 carers of this age within the East Riding who are not registered.
- The impact caring has on younger carers, must also be carefully considered.

5.8.1 Census 2011

Individual ages of carers from the 2011 census is not readily available in the public domain, so working out the average age of an ERY carer is difficult from that particular source. However, later in this section analysis of the East Riding Carers Support Services data does allow us to work out an average age of a registered carer. From the census, age groups are available and are presented below. Table 5.8.1 shows the total number of carers in 2011 by age group, for 1+ hours and 50+ hours of unpaid care. They are also presented as a percentage of the total number of carers, comparing ERY to England. Please note that these age groups have been defined by the NOMIS information system, which reports information about unpaid carers from the 2011 census. Not all age groups are equal in size (some are 10 years, whilst others are 15 years or more).

Table 5.8.1 Unpaid carers by age band. Each age band is shown as a proportion of the total number of carers. 2011 Census. Source: NOMIS

Age Group	1 hour +			50 hours +		
	ERY: Number of Unpaid Carers	ERY: Age band as a % of all unpaid carers (1hr+)	England: Age band as % of all unpaid carers (1hr+)	ERY: Number of Unpaid Carers (50hr+)	ERY: Age band as a % of all unpaid carers	England: Age band as % of all unpaid carers
Age 0 to 15	545	1.5%	2.1%	40	0.5%	0.8%
Age 16 to 24	1,512	4.0%	5.6%	135	1.6%	2.7%
Age 25 to 34	1,986	5.3%	8.7%	381	4.4%	7.9%
Age 35 to 49	8,482	22.7%	26.2%	1,630	19.0%	24.2%
Age 50 to 64	15,197	40.7%	35.5%	2,621	30.5%	27.9%
Age 65 +	9,646	25.8%	22.0%	3,788	44.1%	36.5%
Total	37,368	100.0%	100.0%	8,595	100.0%	100.0%

In ERY, the 50-64 year old age group is shown to provide the largest proportion of 1+ hours of unpaid care at 40.7% (compared to the England average of 30.5%). For 50+ hours of unpaid care, the 65+ age group has the highest proportion (44.1%, compared to the England average of 36.5%). The ERY has a smaller proportion of carers aged 0-49 years compared to England for both 1+ hours and 50+ hours. However, the remaining age groups of 50-64 and 65+ are both significantly larger in the ERY compared to England, suggesting the ERY has an older caring population than England generally. As mentioned earlier in this document, this is perhaps not surprising given that ERY had a higher percentage of older people living within the population than the England average. Charts



A3.12 and A3.13 in the appendix illustrate the differences in the age bands when comparing ERY and England. Using the same methodology as described in section 5.2.1 (which estimated the number of ERY carers in 2016) it is also possible to estimate the numbers of carers by their age group in 2016. This is illustrated in table 5.8.2.

Table 5.8.2 Estimated number of ERY carers mid-year 2016. Applies prevalence of carers in the 2011 census age groups to ONS mid-year 2016 population estimates. Source: ONS/ERY Public Health Intelligence

Age Group	Total ERY Population (2016) [ONS estimate]	Carers as % of each age group 1+hrs (2011 prevalence)	Number est. providing unpaid care (1hr+) in 2016	Carers as % of each age group 50+hrs (2011 prevalence)	Number est. providing unpaid care (50hrs+) in 2016
0-15	55,297	1.0%	540	0.1%	40
16-24	30,519	4.7%	1,443	0.4%	129
25-34	30,786	6.4%	1,972	1.2%	378
35-49	62,501	12.0%	7,523	2.3%	1,446
50-64	74,176	20.7%	15,353	3.6%	2,648
65+	84,417	13.5%	11,396	5.3%	4,475
Total	337,696		38,227		9,116

5.8.2 Age groups of carers registered with the ERY Carers Support Service

Table 5.8.3 uses the same age groups as presented by the NOMIS system in reporting the census, but includes more recent information from the ERY Carers Support Service (August 2017). This latter source does not divide the hours of unpaid care between 1+ hours and 50+ hours as it was not available. It has therefore been assumed that the carers in table 5.8.3 are more likely to relate to those carers providing longer hours (i.e. 50+ hours) but not exclusively. As with the census in 2011, a higher proportion of unpaid carers in the 65+ age group is reported in the table, followed by those aged 50-64.

Table 5.8.3 Age groups of carers registered with ERY Carers Support Service (August 2017). Source: ERY Carers support service

Carers registered with ERY Carers Support Service		
Age Group	Number	Age group as % of all
16-24	27	1.0%
25-34	66	2.3%
35-49	313	11.0%
50-64	968	34.1%
65+	1,466	51.6%
Total	2,840	100%

Median age	65
Mean age	64



Mode age	70
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Table 5.8.3 states that there were 1,466 carers aged over 65 years registered with the East Riding Carers Support Service in August 2017, yet estimates for 2016 (table 5.8.2) suggest there could actually be 3,000 more ERY carers in this age group, who are not registered.

In view of carers getting older as people in general live longer, table 5.8.4 provides a breakdown of the older carer age groups from derived the ERY Carers Support Service (August 2017). Over half (51%) of unpaid carers aged 65+ years fall within the 65-74 age groups and 709 registered carers were aged 75+ years. Very elderly carers (aged 85 years or over) numbered 154, which equated to 5% of the total database; 32 registered carers were aged 90 years or over.

Table 5.8.4 ERY Carers Support Service database (August 2017) ERY respondents aged 65+. Source: ERY Carers support service

Age Group	Count of carers	Age band as % of total sample aged 65+ years	Age Band as % of total sample (all ages)
65-69	357	24%	13%
70-74	400	27%	14%
75-79	307	21%	11%
80-84	248	17%	9%
85+	154	11%	5%
Total aged 65+	1,466	100%	52%

5.8.3 Older Carers (65+ years of age)

This section specifically looks at those unpaid carers aged 65 years of age or over, which this document classes as older or elderly carers.

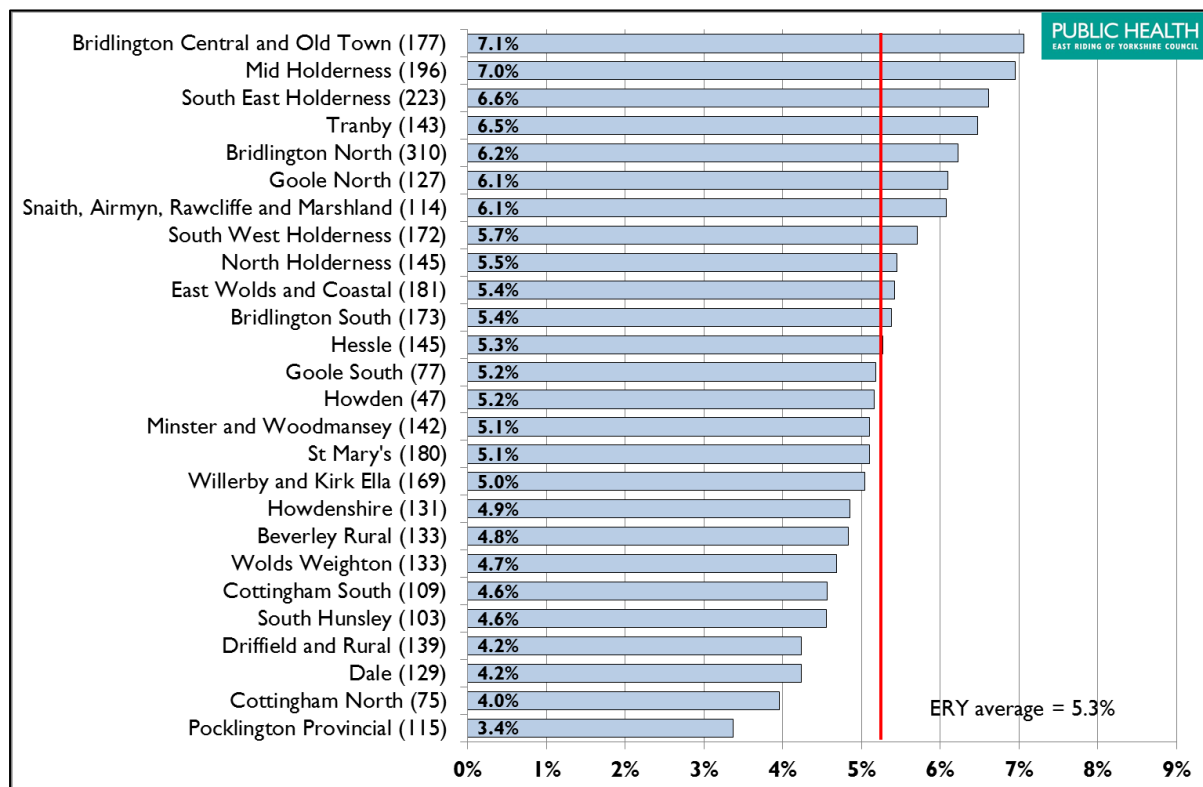
Carers aged 65+ represent almost 26% of all ERY carers providing 1+ hours unpaid care and 44% providing 50+ hours. Table 5.8.2 estimated in 2016 that there was approximately 11,400 ERY unpaid carers aged 65+ years providing 1+ hours care and almost 4,500 providing 50+ hours. However, the number of this age group actually registered with the ERY Carers Support Service was only 1,466. This potentially leaves 10,000 carers aged 65+ (providing 1+ hours) who are not in contact or are unaware of the ERY Carers Support Service.

In 2011, the wards with the five highest count of carers aged 65+ (providing 50+ hours) included: Bridlington North (n=310), South East Holderness (n=223), Mid Holderness (n=196), East Wolds and Coastal (n=181) and St Mary's (n=180). Chart 5.8.5 displays the count of carers in this age group for all ERY wards (the count is in brackets, next to the ward name). The chart also displays 65+ year olds providing unpaid care (50+ hours) in each ward as a percent of all 65 year olds living in the same ward. The wards with the three highest proportions included: Bridlington Central and Old Town (7.1%), Mid Holderness (7%) and South East Holderness (6.5%). Please note the chart is sorted in descending order, based on the percentage of carers in each wards population.

Overall, the percentage of 65+ year olds providing 50+ hours of unpaid care in ERY was 5.3%, the same proportion as England as a whole.



Chart 5.8.5 Unpaid Care by 65+ year olds as a proportion of all 65+ years, 2011, 50+ hours unpaid care. ERY wards compared to ERY average. Actual count of carers in this age group shown in brackets after the ward name. Source: NOMIS



Data held within the ERY Carers Support Service database (August 2017) enabled the calculation of a crude rate of 65+ year old carers per 1,000 population, for each ward. It found slightly different results from the census. St. Mary's, Minster and Woodmansey and South East Holderness were the wards with the three highest rates of carers. Table A3.15 in the appendix, provides full details of this age group's representation within ERY wards.

5.8.4 Unpaid carers aged 65+ projected

The [POPPI website](#) has estimated that the number of unpaid carers aged 65 and over in ERY, will increase to approximately 15,000 people by 2030. This is nearly a 30% increase on the 11,500 unpaid carers of this age group estimated to be within ERY in 2015. This will potentially have a significant impact on services for carers, as more elderly carers present themselves needing support in the future. Please see table 5.8.6 and chart 5.8.7.

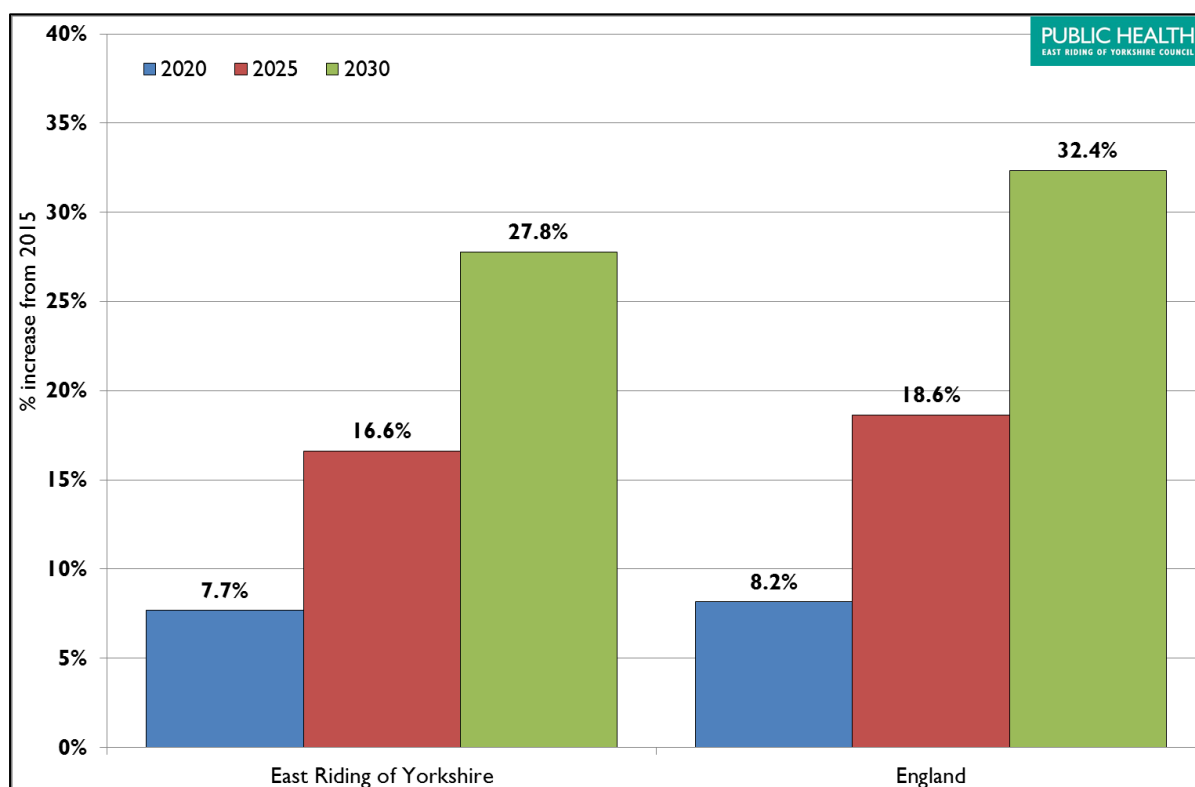
England overall is estimated to experience larger increases over this time period, whilst a similar comparison to ERY's nearest 15 CIPFA neighbours can be found in the appendix (chart A3.16).

Table 5.8.6 Estimated numbers of unpaid carers aged 65+ years, projected to 2030. ERY compared to England. Source: POPPI

Area	Number by year				% increase from 2015		
	2015	2020	2025	2030	2020	2025	2030
ERY	11,620	12,512	13,552	14,848	7.7%	16.6%	27.8%
England	1,384,497	1,497,552	1,642,547	1,832,479	8.2%	18.6%	32.4%



Chart 5.8.7 Projected increase from 2015 of unpaid carers (aged 65+ years). ERY compared to England.
Source: POPPI



5.8.5 Young Carers

Barnardos (2017) define young carers to be “children and young carers under the age of 18 years who provide regular and on-going care and emotional support to a family member who is physically or mentally ill, disabled or misuses substances”. The Children’s Society (2013) found that children acting as unpaid carers tended to underperform at school and as a result can adversely affect their opportunities later in life. This group of carers are also more prone to suffering ill health (Carers UK, 2017), with 40% of carers aged 18-24 having a long term health condition compared with 29% of non-carers in the same age group.

Information available from the 2011 census cannot precisely represent carers aged under 18 years, the two age groups of 0-15 and 16-24 are the nearest available. Earlier in this document table 5.8.2 provided estimated numbers of carers in these age groups for 2016, estimating there were 540 ‘0-15’ year olds and 1,443 ‘16-24’ year olds providing 1+ hours care. For the more intensive 50+ hours category, estimated numbers of carers in these age groups were 40 and 129 respectively.

The prevalence of younger carers within ERY ward (from the 2011 census) are highlighted below. The 5 wards with the highest count of carers, are listed below by age category:

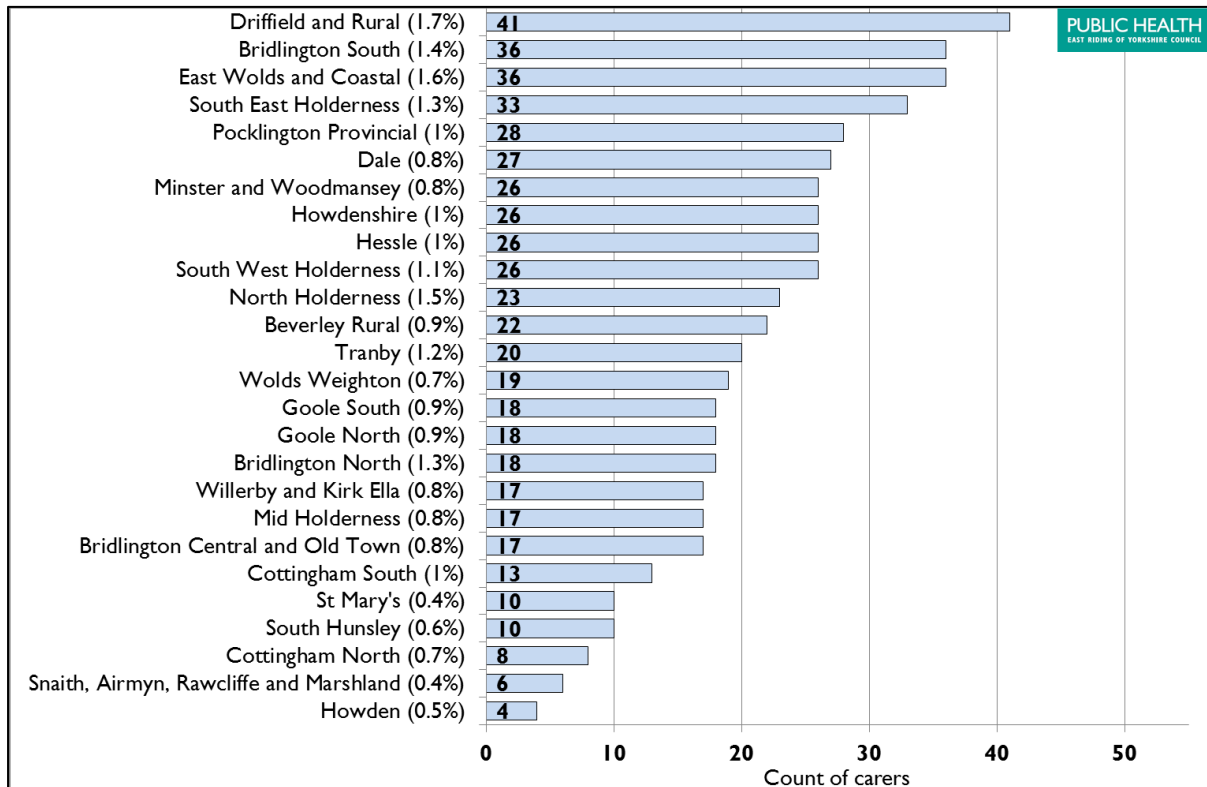
- **0-24 age group:** Driffield and Rural (n=128), South East Holderness (n=127), Hessle (n=126), Bridlington South (n=119) and Minster and Woodmansey (n=105).
- **0-15 age group only:** Driffield and Rural, Bridlington South, East Wolds and Coastal, South East Holderness, Pocklington Provincial (also see chart 5.8.8).



- *16-24 age group only:* Hessle, South East Holderness, Driffield and Rural, Bridlington South, Minster and Woodmansey.

Chart 5.8.8 below, focusses on those carers within the 0-15 age group for each ERY ward, displaying both the number of carers and what percent this number forms in each of the wards overall 0-15 population. Driffield and Rural, East Wolds and Coastal and North Holderness were the three wards with the highest percentages of carers within their population, whilst St. Marys and Snaith had the lowest.

Chart 5.8.8 Count of unpaid carers aged 0-15 in ERY wards, 2011. % in bracket next to ward name indicates count of 0-15 year old carers as % of wards 0-15 population. Source: NOMIS



The youngest person registered with the ERY Carers Support Service in August 2017 was 19 years of age. As it has been established that ERY has had much younger carers than this (via the 2011 census), then young carers will usually access services more specifically aimed at children and young people. However, this again raises the issue of identification and self-identification of carers and is particularly pertinent with this age group. Young carers may feel they are simply “helping mum or dad” (as some may perceive this to be their duty) but in doing so they might not have access to all the support they are entitled to.



5.9 The age of the cared for person

Key points in this section:

- Average age (median) of cared for person in ERY, is 70 years.

The ERY Carers Support Service (August 2017) database reported the median age of the cared for person to be 70 years. Table 5.9.1 provides further detail by age group; almost 60% of cared for persons are aged 65 years or over and a third of all cared for persons are aged 80 years and over. There is presently no publicly available information from the 2011 census which provides the age of the cared for person.

Table 5.9.1 Age of the cared for person, August 2017. Source: ERY Carers support service

Age Group	Count of cared for persons by age group	Age group as % of all cared for persons in database
18-24	152	5%
25-34	167	6%
35-49	332	12%
50-64	514	18%
65+	1,629	58%
Total	2,794	100%
80+	815	29%
90+* (90+ also included in 80+ group above)	196	7%

5.10 The age of the cared for person in relation to the age of the carer

Key points in this section:

- From the age of 35-49 onward, carers predominantly care for people in the same age group
- In May 2017 there were 86 ERY registered carers aged 85+, caring for persons aged 85+

As previously mentioned, carers are becoming older as the people they care for live longer. This section tries to put this into perspective from an ERY point of view; it examines the relationship of the age of the carer with the age of the person who is being cared for.

Chart 5.10.1 uses information sourced from the ERY Carers Support Service August 2017 database. The age group of the carer is plotted against the Y-axis and reveals which are the most dominant age groups of the person they care for (X-axis). The larger proportions are represented by the larger circles. For example, 36% of carers aged 25-34 care for persons who are aged 50-64; whilst 59% of carers aged 75-84 care for persons also aged 75-84. As might be expected, the younger carer age groups (18-24 and 25-34) care for persons older than themselves and were mainly in the 50-64 age group. However, all the other carer age groups (excluding those aged 90+) were predominantly caring for persons within their own age group; for example 41% of carers aged 65-74 were caring for persons also aged 65-74.



Chart 5.10.1 Age group of carer and the age group of the person they care for. Please read text above for interpretation. August 2017. Source: ERY Carers Support Service

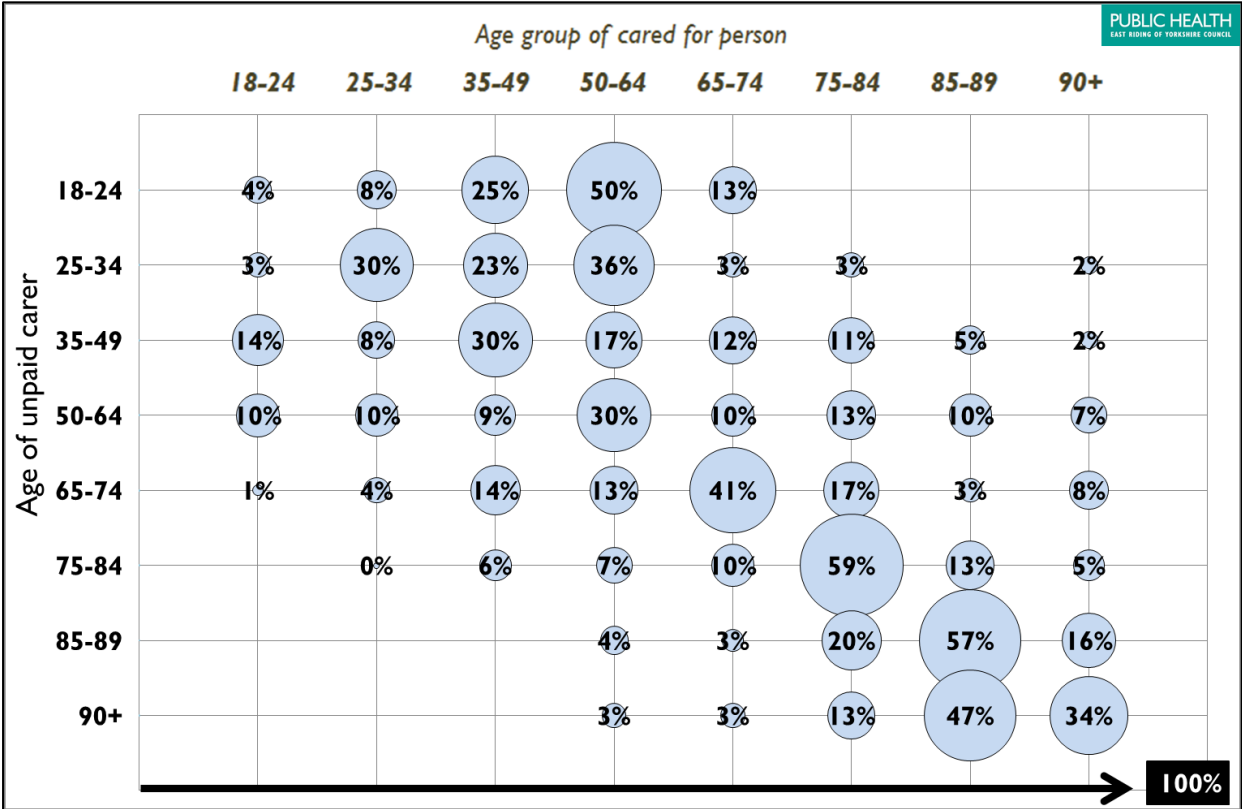
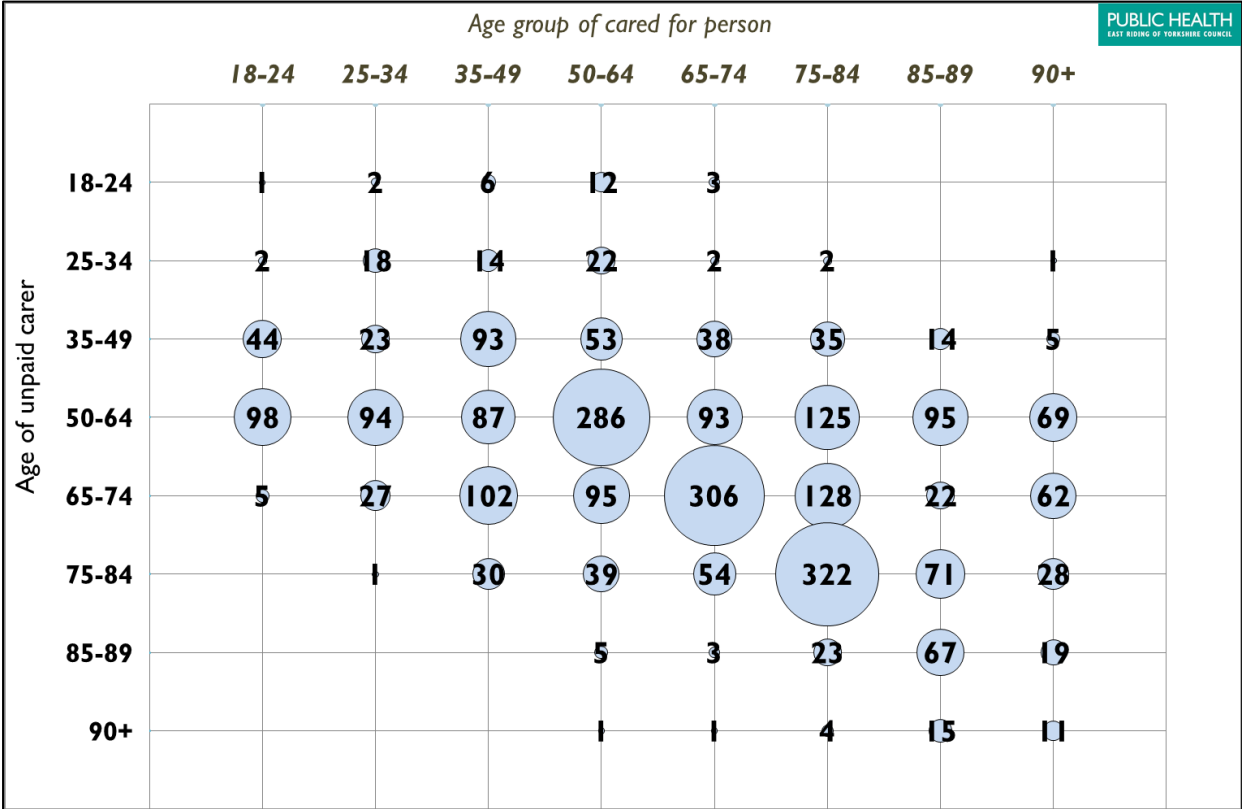


Table 5.10.2 Age group of carer and the age group of the person they care for. Count of carers by age group. August 2017. Source: ERY Carers support service



The interpretation of the percentages in chart 5.10.1 must be viewed with a degree of caution and used in conjunction with chart 5.10.2, which displays the counts on which the percentages are based. For example of the 18-24 year old carer age group, the 50% that were caring for the 50-64 age group was actually based on only 12 out of 24 people. The older age groups of carers, however, provide more robust numbers.

These particular age groups (up to the age of 64) were chosen to reflect those used by NOMIS when reporting carer age groups from the 2011 census. This needs assessment then broke the older age groups down further (rather than relying on one catch-all age group of 65+) to illustrate the numbers of very elderly carers.

Whilst the charts highlight that most carers look after persons in the same age group, it is apparent that there is still potentially 9+ years difference in some of these age groups between carer and cared for person. For example, a 75 year old could be caring for an 84 year old person but they would still be classed as being in the same age group. Further analysis was conducted to compare the carers age against the age of the person they care for, this time using 5 year age bands. The findings reinforced earlier findings by revealing that for carers aged from 35-39 to 85-89 the largest proportion of people they cared for were in the same 5 year age group as themselves. See tables A3.18 and A3.19 in the appendix.

Importantly, the charts and tables present evidence that there are elderly carers who are caring for persons in age groups older than themselves. Almost 100 registered carers aged 70-84 are caring for persons aged 85+ and 19 carers aged 85-89 are caring for persons aged 90+.

5.11 Sandwich carers (carers looking after children and elderly people)

The Carers UK (2012) 'Sandwich Caring' report, raised the issue of an increasing amount of carers bringing up young children at the same time as supporting older parents. In the report it estimated that there were as many as 2.4 million UK carers who found themselves in this situation during 2012. The pressure of these caring roles are particularly acute when combined with the demands of employment and as such (without proper support) will take their toll on issues relating to carer's health, finances, relationships and careers.

For the ERY, the only source of data readily available to investigate this was the SACE 2016/17 database. Of the 582 respondents to the survey, 42 (7%) stated that they had parental responsibility for a child under the age of 18, as well as caring for someone else over the age of 18. The results showed that the ages of the cared for person (by carers who also had responsibility for under 18 year olds) were fairly evenly spread amongst all of the cared for person age groups. Although the number from the survey may appear small, it is anticipated that this figure is much larger amongst the wider ERY carer population who didn't answer the survey.



5.12 The health of carers

Key points in this section:

- *There is an increasing gap between life expectancy and healthy life expectancy (carers are not ageing in good health)*
- *Almost half of carers providing 50+ hours unpaid care, stated their activities were limited a little or a lot*
- *Significantly higher proportion of carers with poor health living in the most deprived wards*
- *Carers referred to Health Trainers predominantly for stress and anxiety*
- *Main conditions prevalent in carers include a long-standing illness and a physical impairment or disability*
- *Carer quality of life score better than region and England, but decreased since previous surveys*
- *Almost 60% of carers state they don't have as much social contact as they would like*
- *Female carers and those carers living in rural areas state that they do not have enough social contact*

5.12.1 Carers health – a national perspective from Carers UK

Carers UK (2017) highlighted the impact that caring had on both the physical and medical wellbeing of carers, with specifics made to back and mobility problems as well as stress, anxiety and depression. Three out of five carers were reported as living with a long term condition and were particularly prevalent in younger carers. Carers reported that they had found it difficult to find time to exercise, eat well or make appointments for medical check-ups. The GP practice of the carer could be an opportunity to provide support or advice, but the numbers of patients identified as carers by practices has decreased. Some practices don't know their patients are carers, or when they do, fail to do anything different in the provision of care. When carers were asked about what would make the biggest difference to their health and wellbeing, the most popular choice was regular breaks from caring.

Breaks from caring are recognised as vital to the carers health and wellbeing, but when asked about taking time off from caring, 25% of carers stated that they had not had a day off for more than 5 years. The carers who were more likely to have had time off, were those who were in employment or were providing palliative care. Barriers relating to taking time for a break included cost, the unwillingness of the cared for person to accept someone else to perform caring duties and the lack of knowledge in how to obtain a break. There was also uncertainty in carers about the quality of the care that would be given in their absence or if there would be sufficient specialist knowledge about the condition that the cared for person had (particularly in relation to palliative care).

5.12.2 The increasing gap between life expectancy and healthy life expectancy

It is well evidenced that nationally, and in the ERY, people are living longer with ERY life expectancy increasing (between 1991/93 to 2013/15) from 73.7 years to 80.2 years for men and 74.7 years to 83.3 years for women. However, although life expectancy has been increasing, 'healthy life expectancy' (an estimate of the average number of years a person is expected to live for in "very good" or "good" health) has not been keeping up at the same rate. Between 2009-11 and 2013-15 the difference between life expectancy at birth and healthy life expectancy at birth increased from



14.8 years to 17.3 years for males and increased from 16.1 years to 17.5 years in females. Charts A3.22 and A3.23 in the appendix illustrate this in more detail.

As a result, those who require care will receive it for longer periods of time. However, as those being cared for become older, so do their carers. Age is one of the main risk factors for the prevalence of disease and as carers become older they are at risk of developing long term health conditions which also require identification, support and management. To summarise, there are (and will continue to be) more older people both providing and requiring care, however those providing the care are not ageing in good health.

5.12.3 General health of the ERY carer (all ages) from 2011 census

When enquiring about residents' general health, the 2011 census asked the question "How is your health in general?" and offered the following categories as responses: 'very good', 'good', 'fair', 'bad' and 'very bad'. This section focusses on the responses made that were 'bad' or 'very bad'. The number of unpaid carers (1+ hours) who reported their health to be bad or very bad health, was in excess of 2,300, equating to a prevalence of 6.3%, significantly lower than the England average of 6.6%. Carers who provided 50+ hours of unpaid care with bad or very bad health numbered approximately 1,100, providing a prevalence of 12.9% (statistically similar to the England average, but twice the percentage reported for ERY carers providing 1+ hour care). Table 5.12.1 provides a summary.

Table 5.12.1 Count of ERY carers by health category. Source: NOMIS

Area	Carer: 1+ hours unpaid care	Carer: 50+ hours unpaid care
	Bad or very bad health	Bad or very bad health
ERY count	2,331	1,107
ERY %	6.3%	12.9%
England %	6.6%	13.0%

Charts A3.24 and A3.25 in the appendix provide a comparison with the nearest 15 CIPFA neighbours to ERY. In both charts ERY is (generally) centrally placed amongst its peers, which are both topped by Wirral local authority in having the largest proportion of 'bad' or 'very bad' health within its unpaid carer population.

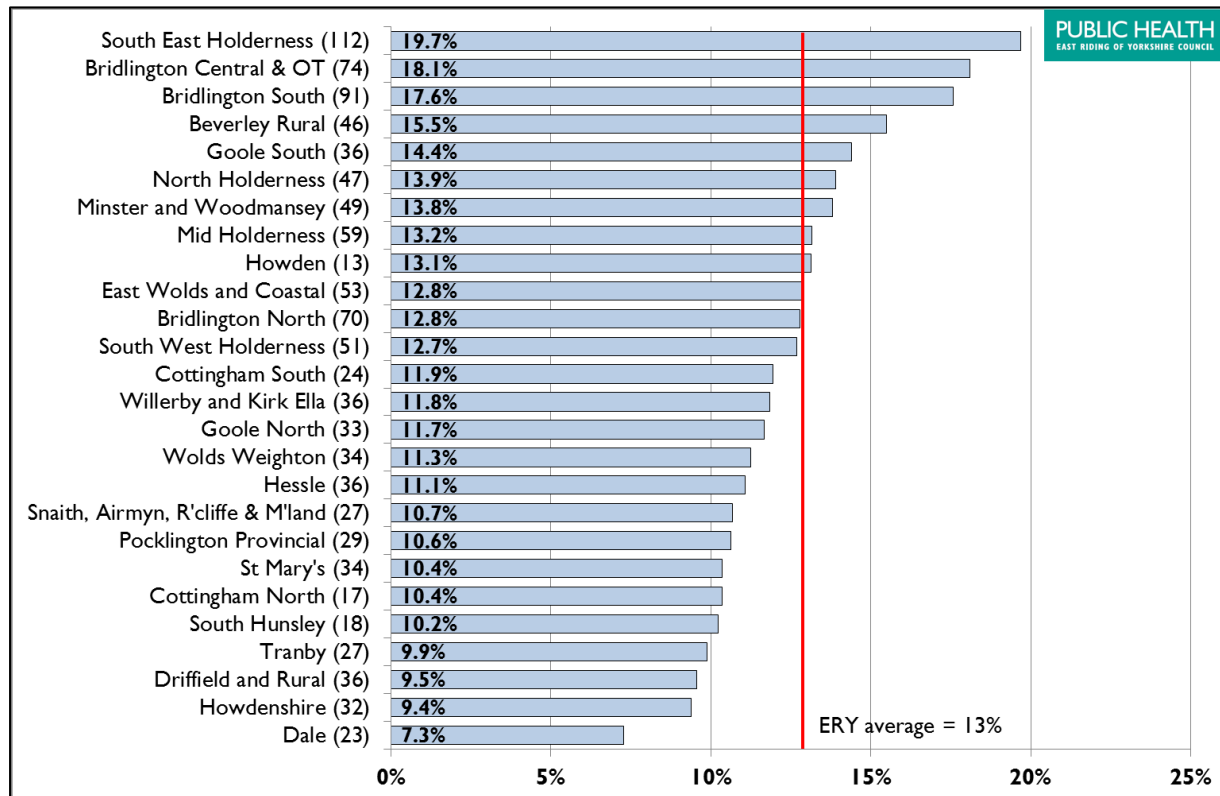
The prevalence of bad or very bad health within the wards of ERY is shown in chart 5.12.2, for 50+ hours unpaid care (for 1+ hours, please see chart A3.26 in the appendix). Both charts reveal that it is (generally) the most deprived wards of ERY which have the highest proportions of bad or very bad health. Three wards were significantly higher than the ERY average for carers who conduct 50+ hours of unpaid care: South East Holderness (19.7%, n=112), Bridlington Central and Old Town (18.1%, n=74) and Bridlington South (17.6%, n=91).

One area of concern to be drawn from chart 5.12.2 is not just viewing the prevalence of poor health, it is at the same time being aware that not all carers are registered (please refer back to section 5.2). Therefore how many carers are living within ERY in bad or very health, but are not in touch with services? South East Holderness ward can be used as an example with chart 5.12.2 illustrating 1 in 5 carers reporting bad or very bad health. There were 578 carers in the ward recorded as providing 50+ hours unpaid care in 2011, but only 194 carers (i.e a third) were actually



registered as of May 2017. What services are the unregistered two-thirds of carers receiving if 20% of them have bad or very bad health?

Chart 5.12.2 Percent of unpaid carers (50+ hours per week) who said their health was bad or very bad, 2011. ERY wards compared to ERY average. Actual count of carers with bad/very bad health is in brackets next to ward name. Source: NOMIS



For 1+ hour of unpaid care there were five wards significantly higher than the ERY average regarding health being bad or very bad: Bridlington Central and Old Town (11.6%, n=144), South East Holderness (10.7%, n=202), Bridlington South (10.4%, n=161), Goole South (9%, n=81) and Bridlington North (7.6%, n=140).

Table A3.29 in the appendix, displays the number of unpaid carers (1+ hours and 50+ hours) whose health is bad or very bad, for each ERY ward.

5.12.4 Day-to-day activities limited because of a health problem or disability (all ages)

Some health problems and disabilities can be long-lasting and as a result reduce a person's ability to carry out normal day to day activities. In the case of unpaid carers, being limited by activity restriction will not only affect themselves but potentially the person they care for too.

The 2011 census asked about conditions that have lasted or were expected to last for at least a year. The specific question was: "Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months?" Over 10,000 unpaid carers in the ERY (providing 1+ hour of unpaid care) reported that their activities were either limited a little or a lot. This equated to 27.6% of the total 1+ hour unpaid carers, significantly higher than the England average of 26.7%. Compared to the nearest CIPFA neighbours, ERY was within the top



third of highest values and was one of six local authorities significantly higher than the England average. Please see chart A3.27 in the appendix.

Table 5.12.3 provides a summary for ERY with a comparison to the England average.

Table 5.12.3 Count and percent of unpaid carers whose day-to-day activities limited because of a health problem or disability. ERY compared to England, 2011. Source: NOMIS

Area	Carer: 1+ hours unpaid care	Carer: 50+ hours unpaid care
	Activities limited a little/lot	Activities limited a little/lot
ERY count	10,280	3,863
ERY %	27.6%	45.1%
England %	26.7%	42.4%

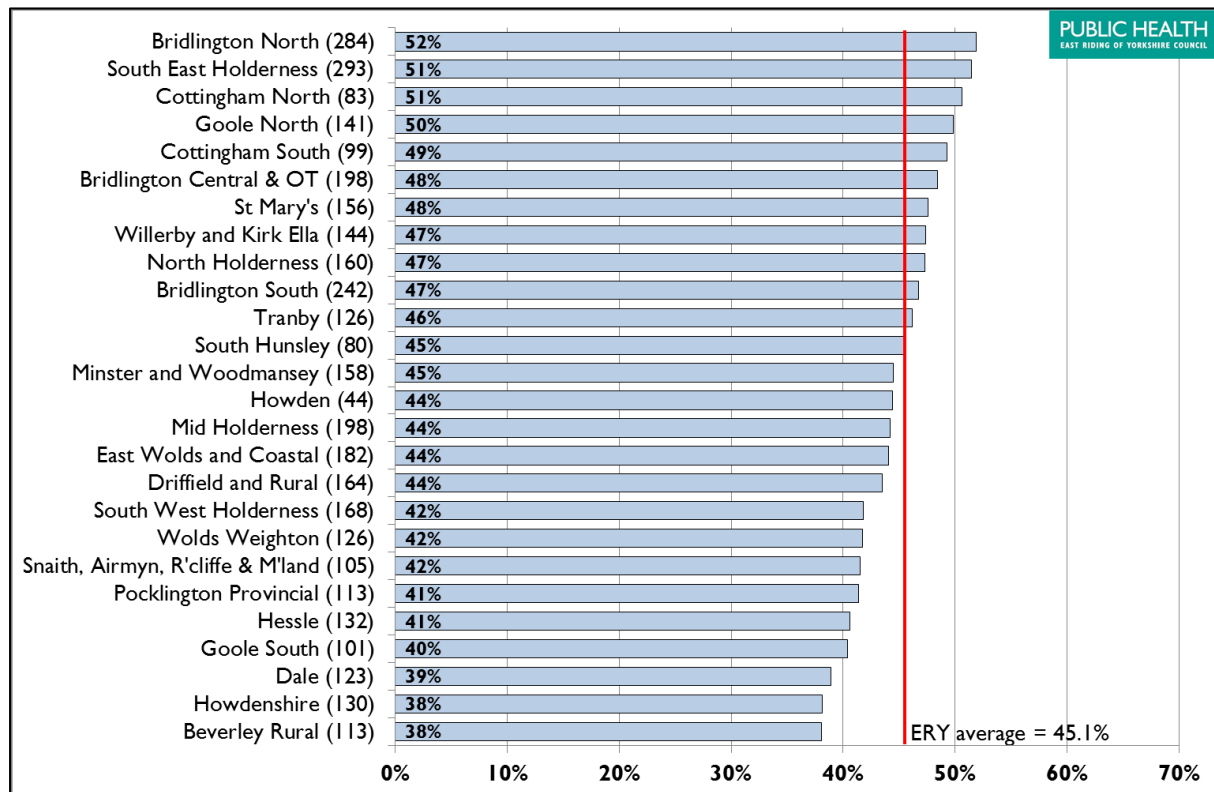
Within the ERY, six wards had a significantly higher proportion of unpaid carers (1+ hours) whose activities were limited, compared to the ERY average. These included the three wards of Bridlington which had the highest percentages of all the wards, headed by Bridlington Central and Old Town with a prevalence of almost 37% (n=457). The other three significantly higher wards (South East Holderness, North Holderness and Goole North) are also generally more deprived. In contrast, the least deprived ward of ERY (South Hunsley) had a prevalence of 21% (226). Table A3.29 in the appendix displays all of the ward percentages for 1+ hours and 50+ hours.

Table 5.12.3 also shows that for those carers providing 50+ hours per week, the proportion whose activities were limited a little or a lot rose to 45.1% (almost half), significantly higher than the England average of 42.4%. ERY had the second highest percent compared to the nearest 15 CIPFA neighbours, one of seven that were significantly higher than England. Please see chart A3.28 in the appendix.

Bridlington North and South East Holderness were the ERY wards with the higher prevalence of unpaid carers (50+ hours) with limited activity at 51.9% (n=284) and 51.5% (n=293) respectively. These are amongst the most deprived wards within ERY. Beverley Rural had the lowest prevalence (38%, n=113) and is amongst the least deprived wards of ERY. Please see chart 5.12.4.



Chart 5.12.4 Percent of unpaid carers (50+ hours per week) who said their activities were limited a little or a lot, 2011. ERY ward compared to ERY average. Actual count of carers whose activities were limited a little or a lot is in brackets next to ward name. Source: NOMIS



5.12.5 Carers referred to the Health Trainers by the Carer Support Service

Health Trainers provide one to one support and motivation to adults (including carers) across the East Riding of Yorkshire. The service is designed to help adults make healthy lifestyle changes through guidance and tailored lifestyle programmes.

Table 5.12.5 provides a quarterly breakdown, between October 2015 and March 2017, of the count and percent of carers seen by the ERY Carers support service, who are then referred to the Health Trainers.

Before any meaningful analysis can be conducted on this particular section more data is needed so that, for example, annual trends can be examined and interpreted. From the information presented so far, the quarterly percentage of carers assessed and then referred to Health Trainers had been increasing between quarter 4 2015/16 and quarter 3 2016/17 with actual numbers of carers referred varying between 12 and 30 per quarter, during this period.



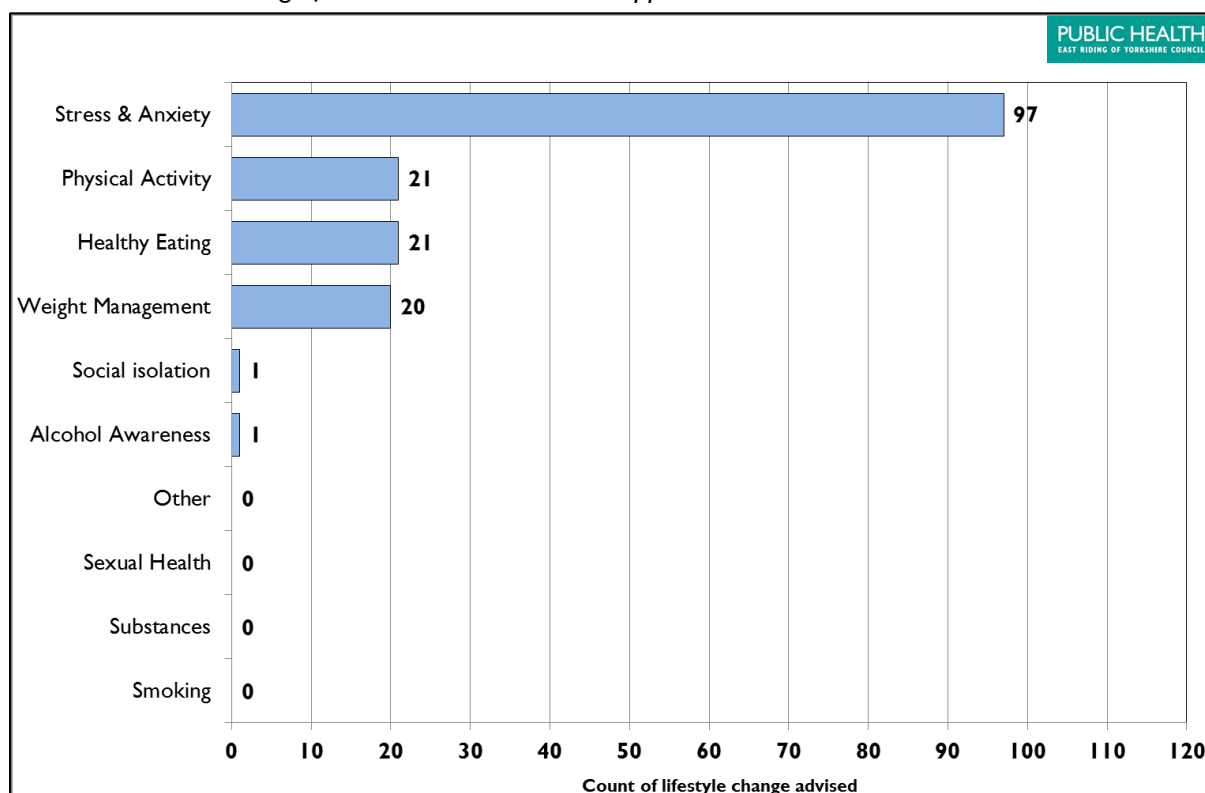
Table 5.12.5 Percent and count of carers assessed and referred to Health Trainers. Source: East Riding of Yorkshire Council Carers Support Service

Quarter period	Percent of carers assessed and then referred to Health Trainers	Count of carers referred for Health Trainers
October - December 2015	14%	15
January - March 2016	8%	12
April - June 2016	11%	30
July - September 2016	13%	28
October - December 2016	26%	24
January - March 2017	19%	15

The reason for the referral to the Health Trainers is displayed in chart 5.12.6, which displays the type of need/lifestyle change required.

There are four main reasons shown on the chart, with 'stress and anxiety' clearly dominating; others referral needs include 'physical activity', 'healthy eating' and 'weight management'. In the future, it will be useful to compile further time periods of this information with the existing data, so that a more robust data set exists.

Chart 5.12.6 Referrals made to Health Trainers, count of need type/lifestyle change. October 2015 to March 2017. Source: East Riding of Yorkshire Council Carers Support Service



5.12.6 The carer: health conditions reported (SACE 2016/17)

Carers UK (2017) reported that a recent GP patient survey found 3 in 5 carers to have a long term health condition. In the 2016/17 SACE survey, question 24 asked the carer about their health and if they had any of the conditions listed in table 5.12.7. Out of the 520 ERY unpaid carers who responded to the question, approximately 57% reported as having at least one of the health conditions listed. Almost a quarter of the 520 respondents were reported to have more than one of the conditions.

Table 5.12.7 displays the type of condition, along with the proportion of carers who reported having it. Some conditions have a very general description (e.g. 'a long-standing illness'), which could cover a multitude of conditions. The health condition called 'a long standing illness' was most frequently reported by carers (31.2%), followed by 'a physical impairment or disability' (22.6%) and 'sight or hearing loss' (16.1%).

The table also compares ERY to the regional and national averages. ERY carers reported to have a higher prevalence of 'a long-standing illness' and 'a physical impairment or disability' than both region and England. In contrast, ERY had a lower prevalence of carers with conditions classified as 'other', 'a mental health problem/illness' and 'a learning disability/difficulty'.

Table 5.12.7 SACE survey 2016/17, reported health conditions by carers. Source: SACE survey

Condition	ERY	Yorkshire and Humber	England
A long-standing illness	31.2%	29.9%	28.6%
A physical impairment or disability	22.6%	19.8%	20.6%
Sight or hearing loss	16.1%	15.9%	16.7%
Other	10.2%	11.3%	12.2%
A mental health problem or illness	7.9%	8.7%	8.9%
A learning disability or difficulty	1.9%	2.4%	2.7%
None of the above	43.5%	41.4%	39.9%
Respondents (who answered question)	520	5,420	51,345

5.12.7 Carer-reported quality of life

This indicator aims to gain an overarching view of the quality of life of carers and according to PHE it is the only current measure available related to quality of life for carers. The responses to six questions from the Carers Survey are combined to give an overall score, out of a possible 12. These questions are based on six themes: occupation, control, personal care, safety, social participation and encouragement and support. When analysed individually, the responses to the questions are designed to indicate if the carer has needs that are not being met, within any of these themes. The questions asked are listed in detail in table A3.30 in the appendix.

Table 5.12.8 provides comparative information from the three SACE surveys.



Table 5.12.8 Carer-reported quality of life from SACE survey (score out of 12). ERY compared to region and England (where available). Source: PHE

Period	ERY	Yorkshire and the Humber	England
2012/13	8.4	8.3	8.1
2014/15	8.2	8.1	7.9
2016/17	8.1	8.0	7.7

The carer reported quality of life score for ERY in 2016/17 was 8.1, lower than previous years but higher than both the regional and England averages (significance testing is not presently available for the latest period). Like the regional and England average, the ERY quality of life score has decreased year on year since 2012/13. In 2014/15 the ERY score of 8.2 was significantly higher than the England average of 7.9 (see chart A3.31 in the appendix) and was within the top third of scores when compared with the nearest 15 CIPFA neighbours.

5.12.8 The percentage of adult carers who have as much social contact at they would like

Addressing the issues of loneliness is a key ERY JSNA priority; its association with poor health from both a mental and physical perspective has been well evidenced (NICE, 2015). A core aim in the ERY is to support residents (including carers) to remain connected with their communities and to maintain connections with family and friends.

In the SACE survey (question 11), carers were asked "thinking about how much contact you have had with people you like, which of the following best describes your social situation?" From the 2016/17 survey 40.6% of ERY carers (see table 5.12.9) responded by saying they had as much social contact as they wanted, an increase on the previous survey but almost 8% lower than 2012/13. This latest result was higher than the regional average and significantly higher than proportion reported for England as a whole.

In comparison with the CIPFA neighbours, ERY was within the top half of values compared to its peers and was one of six local authorities that had a significantly higher proportion than the England average. Please see chart A3.32 in the appendix to see the CIPFA comparison.

Table 5.12.9 Percentage of adult carers who have as much social contact at they would like. ERY compared to region and England (where results are available). Source: PHE

Period	ERY %	Yorkshire and the Humber %	England %
2012/13	48.2%	44.4%	41.3%
2014/15	39.7%	40.5%	38.5%
2016/17	40.6%	38.7%	35.5%

However, if 40.6% of respondents in ERY state they have as much contact as they would like then this still leaves 59.4% (of the 572 carers who answered the question) who do not. More specifically 44.8% (n=256) answered the question with a response of "I have some social contact with people but not enough" and 14.7% (n=84) stated "I have little social contact with people and feel socially isolated".

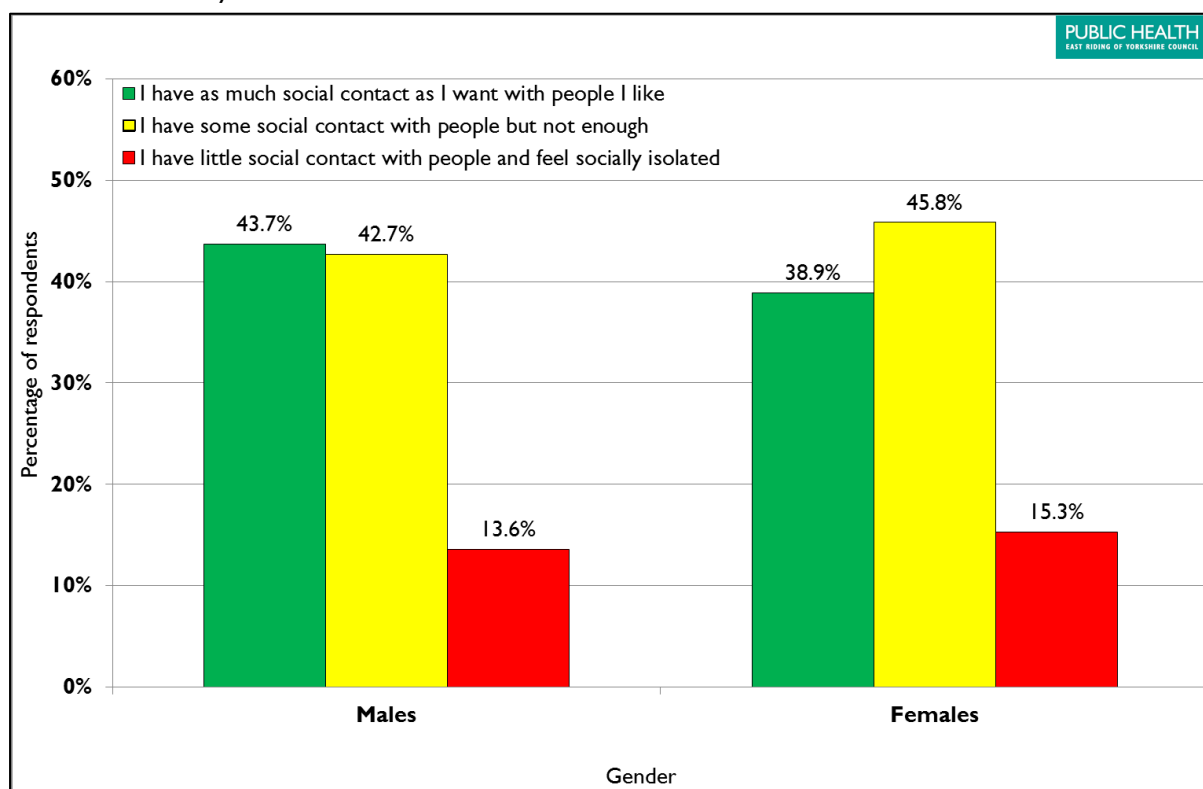


Chart 5.12.10 displays the difference in responses to the question about social contact, by gender. A higher proportion of males (43.7%) stated that they *did* have as much social contact as they would like, compared to females (38.9%). This was the category with the largest proportion for males, whereas for females the highest proportion was that they had ‘some social contact with people but not enough’.

Respondents who answered that they had ‘little social contact and felt socially isolated’ formed the category with the lowest percentages (13.6% for males and 15.3% for females). However, it is worth highlighting that even though this category formed the lowest proportion, at 14.7% (males and females combined) it means that 1 in 7 carers from the survey reported that they had little social contact and felt socially isolated. With section 5.2 estimating there to be over 38,000 carers in the ERY providing 1+ hours unpaid care and over 8,500 providing 50+ hours, this prevalence of carers with little social contact and feeling socially isolated is particularly pertinent. When simply looking at the latter group of carers (50+ hours), who provide possibly some of the most acute amount of unpaid care, it could mean that over 1,200 of them find themselves lacking social contact and are isolated.

Chart 5.12.10 SACE 2016/17: Responses to Question 11 about social contact, by gender. ERY residents.

Source: SACE survey



The SACE survey data also enables analysis by geographic area. Chart 5.12.11 illustrates the responses made to the question about social contact, by residents in rural and urban areas. In rural areas, the category with the highest percentage was ‘I have some social contact but not enough’; almost half of rural residents (48.1%) responded to state this was applicable to them. This was in contrast to the 36.6% of rural residents stating they had as much social contact as they would like.

Within the urban city and town areas, the highest percent of responses from carers stated that they ‘had as much social contact I want with people I like’ (44%). Both geographic areas had a similar



percentage of carers who had little social contact and felt socially isolated. Perhaps the most notable difference between the two geographic areas was the larger percentage difference in rural areas between the 'I have as much social contact' and the 'I have some contact' categories (36.6% and 48.1% respectively).

Chart 5.12.11 SACE 2016/17: Responses to Question 11 about social contact, by area of residence (urban/rural categories). ERY residents. Source: SACE survey

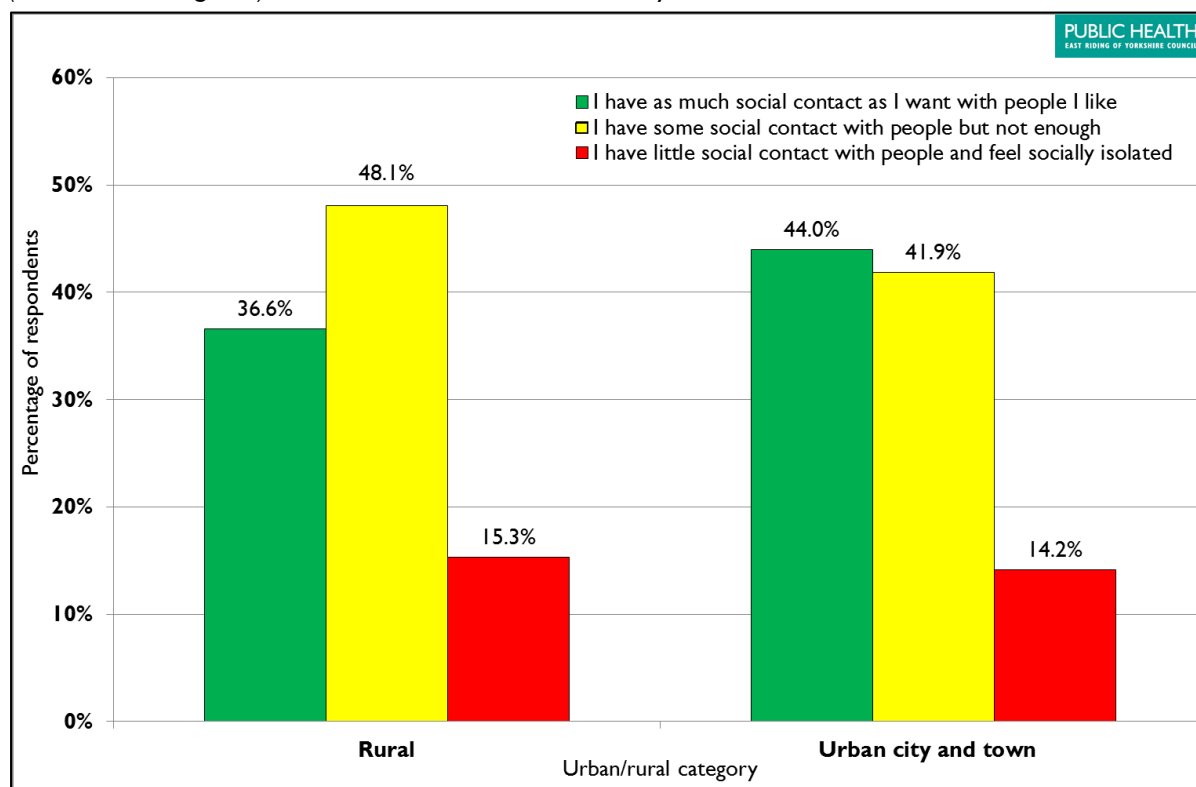


Chart A3.33 in the appendix divides the rural areas into the smaller categories of 'rural village' and 'rural town and fringe' and displays the results for the social isolation question. Both categories display similar proportions as found with the overall 'rural' category displayed in chart 5.12.11 above. The 'rural hamlets and isolated dwellings' category (where residents are potentially most at risk from social isolation) was not included as only 20 survey responses were made from these areas, with counts as low as 3 in response to some of the answers to the question.

Similarly, analysis is not presented here at individual ward level due to small numbers. However by grouping the wards together into the old (and now defunct) CCG localities previously used in JSNA analysis, it was possible to work with more robust numbers. Chart A3.34 in the appendix displays the responses to SACE question 11 about isolation, by each locality. Bridlington was noticeably the only locality whose residents gave the answer 'I have as much social contact I want with people I like' the highest count (equating to 48.5%). Another observation of interest was that the Haltemprice locality (made up of the West Hull villages and the rural areas of Dale amongst others) had the highest percentage of carers who had little social contact and felt socially isolated (20%, or 1 in 5 carers). Holderness experienced the widest gap between the 'I have as much social contact...' and the 'I have some social contact' categories, at 37% and 48.9% respectively. Holderness was also the locality which had the highest percentage of carers stating 'I have some social contact with people but not enough'. Map A3.5 in the appendix displays the wards grouped into their localities.



5.13 The cared for person: reported needs and health conditions

Key points in this section:

- Most prevalence primary support need is 'Physical Support: Personal Care Support', followed by 'Mental Health Support'
- Most prevalent conditions include: 'A physical disability', 'Long-standing illness' and 'Problems connected to ageing'
- Over 70% of cared for persons in survey had more than one condition
- Some cared for persons have as many as 7 conditions

5.13.1 ERY Carers Support Service database August 2017

The categories listed in table 5.13.1 are the primary support reasons for the person being cared for and are normally recorded by the Carer Support Service once they have completed the Carer's assessment for the carer.

The support need category with the highest prevalence was the 'Physical Support: Personal Care Support', with 65% of cared for persons (n=1,791) in the database reported as having this need. The second and third highest support needs of 'Mental Health Support' and 'Learning Disability Support' were much smaller in proportion (12.9% and 10.7% respectively).

Table 5.13.1 ERY Carers Support Service database August 2017, reported health conditions of cared for person. Source: ERY Carers Support Service

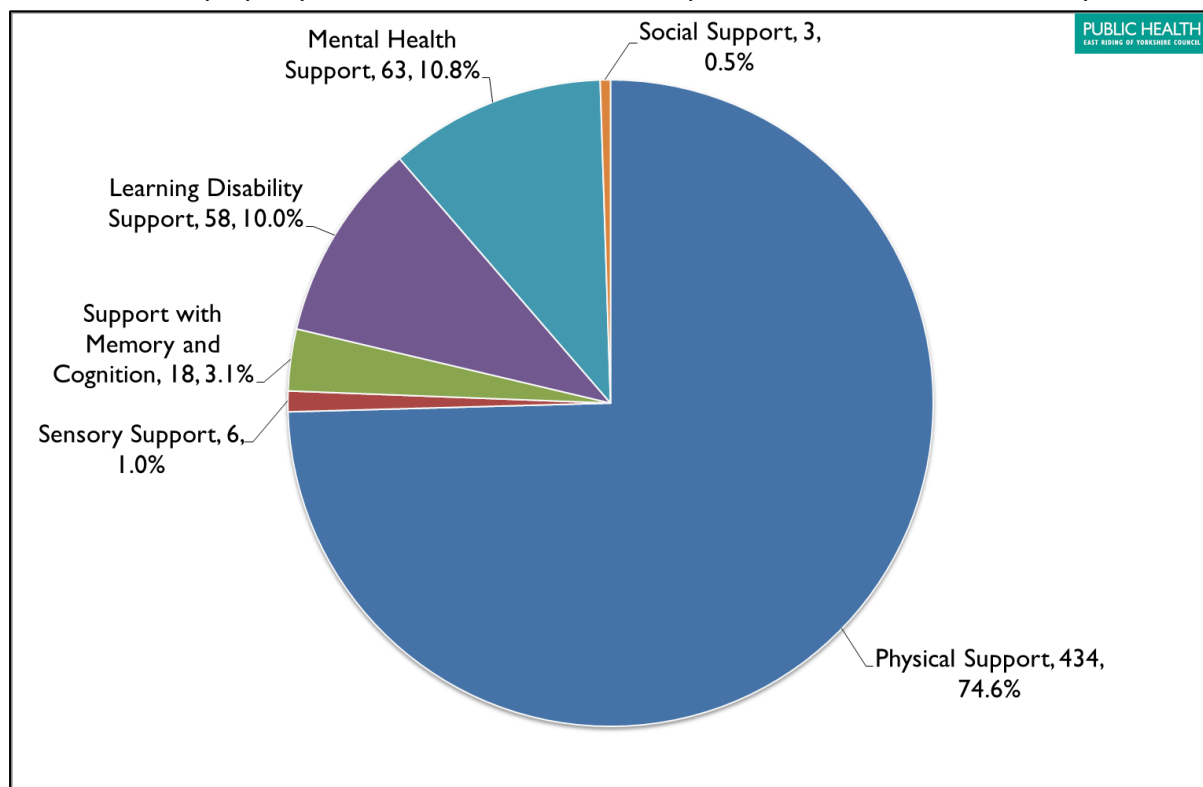
Support need category	Count of cared for persons	% of total
Physical Support: Personal Care Support	1,791	64.6%
Mental Health Support	357	12.9%
Learning Disability Support	298	10.7%
Physical Support; Access And Mobility Only	121	4.4%
Support With Memory And Cognition	91	3.3%
Sensory Support; Support For Visual Impairment	27	1.0%
Sensory Support; Support For Hearing Impairment	23	0.8%
Social Support; Support To Carer	21	0.8%
Social Support; Support For Social Isolation/Other	19	0.7%
Adult Frailty	8	0.3%
Social Support; Substance Misuse Support	5	0.2%
(Others with a count of less than 5)	12	0.4%
Total	2,773	100.0%

5.13.2 The cared for person: primary support reason and specific conditions (SACE 2016/17 survey)

The 2016/17 SACE survey provides another source of information to report the main support need for the cared for person. Like the ERY Carers Support Service database (albeit with slightly different proportions), the SACE survey reported the top three needs as physical support (74.6%), mental health (10.8%) and learning disability (10.0%). Chart 5.13.2 illustrates this further.



Chart 5.13.2 SACE 2016/17: Primary support reason for cared for person. Chart displays support reason name, number of people by each reason and the reason as a percent of total. Source: SACE survey



As well as enquiring about the main support need, the SACE survey also asked if the cared for person had one or more specific conditions. The results are displayed in table 5.13.3.

Table 5.13.3 SACE survey 2016/17 reported conditions of the cared for person. Source: SACE survey

Condition	ERY	Y&H Region	England
A physical disability	58.2%	52.1%	53.1%
Long-standing illness	50.9%	40.1%	40.0%
Problems connected to ageing	34.5%	34.7%	35.2%
Sight or hearing loss	31.8%	31.3%	30.2%
Dementia	23.4%	31.6%	35.1%
A mental health problem	23.3%	19.3%	20.5%
A learning disability or difficulty	14.9%	20.7%	19.3%
Terminal illness	6.8%	4.7%	5.2%
Alcohol or drug dependency	1.2%	1.5%	1.6%
Respondents	575	5,805	54,870

The conditions (in ERY cared for persons) with the three highest prevalence values included 'a physical disability' (58.2%), 'long-standing illness' (50.9%) and 'problems connecting to ageing' (34.5%). The first two conditions were higher than both the England and regional values, other conditions that were also higher in ERY than the two other comparators included: 'sight and hearing loss', 'a mental health problem' and 'terminal illness'.

Nationally, it has been well evidenced that the cared for often don't just have one need or one long term condition, they can often have several. Table 5.13.3 above, reported the proportion of people with each condition, but didn't reveal how many people had more than one condition.



This is partially explored in table 5.13.4, but is reliant on how the person completing the survey interprets the definition of a condition. For example, a carer can report that the person they care for has both a 'long-standing illness' and also a 'problem connected to ageing'. However, there is no indication if the carer is actually talking about the same condition but reporting them as two separate conditions.

Most persons cared for, had 1-3 conditions from the list in table 5.13.4, which represented 80% of the responses (n=462); however this still left 20% (n=114) living with 4 or more conditions. There were 3 cared for persons reported to have 7 of the conditions.

Table 5.13.4 Number of conditions prevalent in individual cared for persons. Source: 2016/17 SACE survey

Number of conditions	Count of responses	% of total
1	165	28.6%
2	147	25.5%
3	150	26.0%
4	80	13.9%
5	25	4.3%
6	6	1.0%
7	3	0.5%
Total*	576	100%

The next part of the analysis attempted to examine which reported co-morbidities were more prevalent with one another. Charts 5.13.5 and 5.13.6 display this; one chart presents the relationship as percentages and the other as a count, however they are both based on the same information. Please note that the percentages in chart 5.13.6 are not intended to add up to 100%.

To illustrate how the charts should be interpreted, three examples are provided below:

- See chart 5.13.5. Of the 135 people reported to have dementia, 72 had 'problems connected to ageing', 56 had a 'physical disability' and 50 had 'sight or hearing loss'. Chart 5.13.6 presents these co-morbidities as a percentage, so of the 135 people reported to have dementia 53% of them had 'problems connected to ageing', 41% had a 'physical disability' and 37% had 'sight or hearing loss'.
- Of the 335 persons reported to have a physical disability, 199 of them (59%) experienced a 'long-standing illness', 134 (40%) had a physical disability and 124 (37%) had 'sight or hearing loss'.
- There were 134 cared-for persons who were reported to have a 'mental health problem', 68 of them (51%) also had a 'physical disability', 67 (50%) had a 'long standing illness' and 38 (28%) had an issue relating to 'sight or hearing loss'.

However, there should be some precaution taken when interpreting the percentages in the chart, based on small numbers. For example, chart 5.13.6 states that 71% of cared for persons with an alcohol or drug dependency also have a mental health condition. This percent is actually only based on 5 persons reported to have a mental health condition out of the 7 persons who reported to have alcohol or drug dependency issues.



Table 5.13.5 Cared for person condition (left) with co-morbidity (top). Count. Source: SACE survey 2016/17

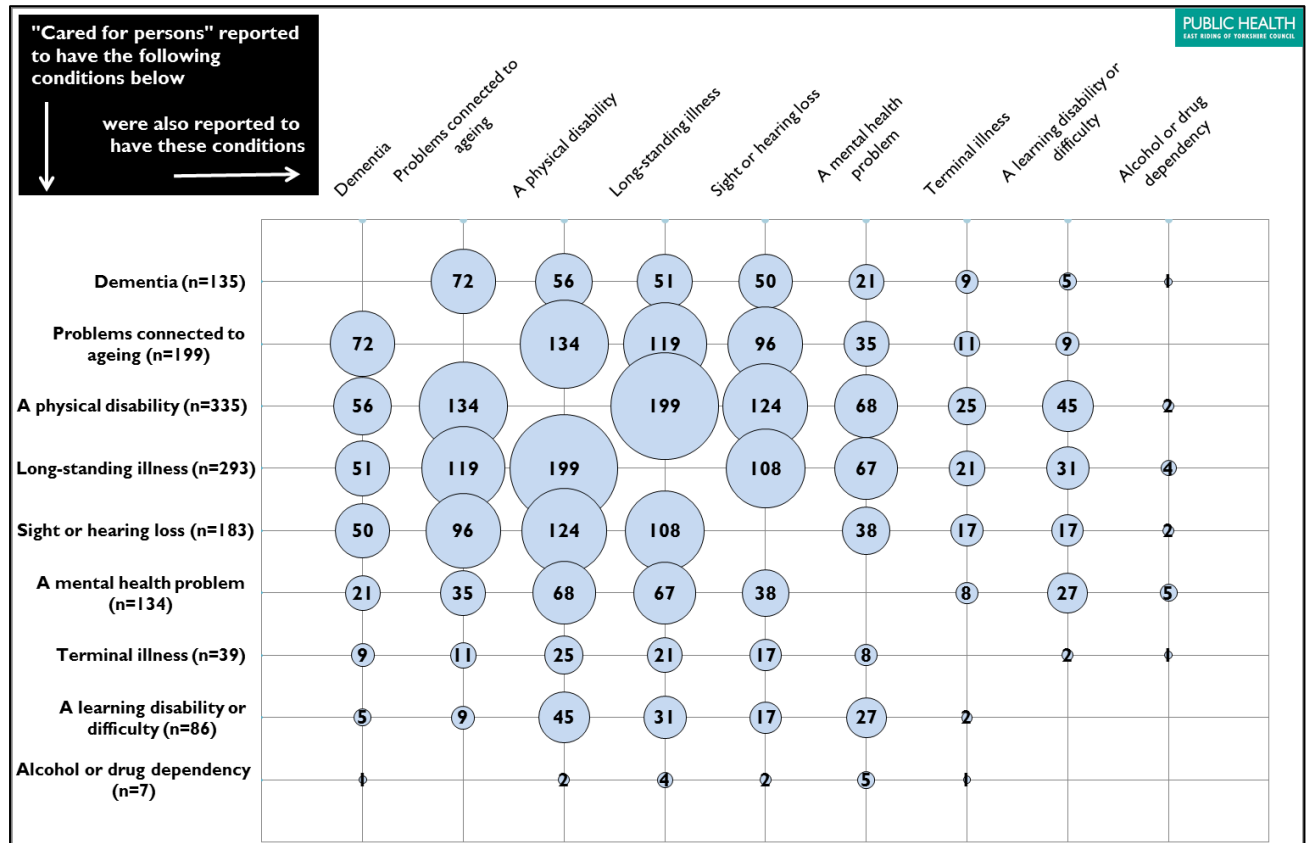
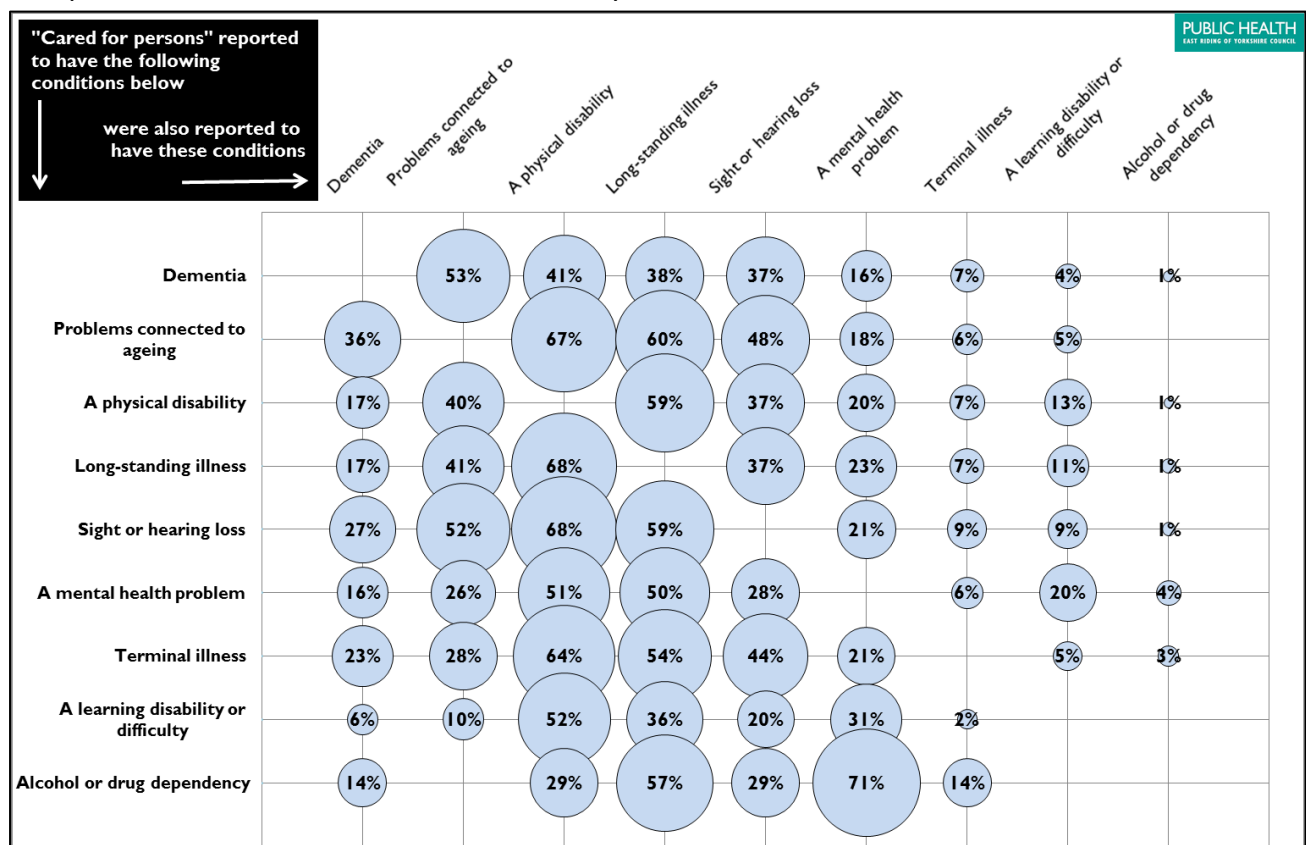


Table 5.13.6 Cared for person condition (left) with co-morbidity (top). Percent. Please note percentages do not add up to 100% for each condition Source: SACE survey 2016/17



5.14 Carers interaction with services

Key points in this section:

- Results suggest ERY carers have a positive experience with services, but these are only likely to be the opinions of those who actually make themselves known to be carers
- ERY has a higher rate per population of carers receiving assessments than England average
- The percent of ERY carers reporting satisfaction of carers with social services is higher than the regional and England averages
- However in 2016/17 almost 57% of carers stated they were not entirely satisfied with social services
- Higher percentage of ERY carers reporting that they have been consulted in discussion about the person they care for than regional and England averages
- However, 39% of Holderness carers stated that they had not always or not usually been included or consulted in discussion about the person they care for
- Higher percentage of ERY carers find it easy to find information about services than regional and England averages, yet 3 out of 10 ERY carers still do not find it easy to find information about services

5.14.1 Adult carers receiving assessments

A carer's assessment provides an opportunity for the local authority to engage with the carer and allow the carer to discuss the level of support they need or the services that they require. Usually an assessment examines how caring affects the life of the carer (including physical, mental and emotional perspectives) and whether they are able or willing to carry on performing the caring role.

This indicator counts the number of adult carers (aged 18 years and over) for whom assessments or reviews were completed throughout the specified year and then converted to a rate per 100,000 population (aged 18 years and over) for comparison purposes. It should be noted that this does not take account of the total number of carers within the population, as assessments are usually restricted to new carers coming to the attention of local authority services.

Table 5.14.1 shows in 2013/14 there were almost 3,300 assessments carried out in ERY, equating to a rate of 1,203 per 100,000 population, a significantly higher rate than the national average. The ERY rate in this period was second highest, when compared against the nearest 15 CIPFA statistical neighbours, suggesting ERY is more successful in performing assessments with new carers than most other similar areas. Please refer to chart A3.35 in the appendix.

Table 5.14.1 Adult carers receiving assessments per 100,000 population, ERY compared to England, 2010/11 to 2013/14. Source: PHE

Period	Count	ERY Crude Rate per 100,000 population	England crude rate per 100,000 population
2010/11	3,215	1,194	1,076
2011/12	4,085	1,509	1,027
2012/13	3,175	1,167	977
2013/14	3,280	1,203	968



5.14.2 People who care for an adult with a mental health condition and were assessed during the year

Similarly to the section above, this indicator examines the rate of carer assessments in ERY but more specifically for adult carers of adult mental health clients (aged 18-64). This indicator also counts those carers who declined assessments.

Table 5.14.2 displays the counts and rate for two financial years, the latest year available (2013/14) found the ERY rate of carer assessments of adult mental health clients to be significantly higher than the national average and the second highest local authority amongst its CIPFA peers (see chart A3.36 in the appendix).

Table 5.14.2 Adult carers of adults with a mental health condition receiving assessments per 100,000. ERY compared to England, 2010/11 to 2013/14. Source: PHE

Period	Count	ERY Crude Rate per 100,000 population	England crude rate per 100,000 population
2012/13	305	112.1	68.2
2013/14	325	119.2	64.3

5.14.3 Overall satisfaction of carers with social services

This indicator examines the satisfaction of carers with the services they receive from adult social care. PHE believe that the reported satisfaction with services is a suitable predictor of the overall experience of the services and their quality.

From the SACE survey, question 4 asked carers how satisfied they were with the services and support they received from social services, during the past 12 months. In 2016/17 43.1% of ERY carers replied that they were either extremely satisfied or very satisfied. Whilst this was a higher (but statistically similar) percentage than both regional and national comparators, it was a lower than the 45.9% reported by ERY carers during 2014/15, which in turn was lower than the 2012/13 result of 51.7%. However for 2016/17, it perhaps worryingly highlights that almost 57% of the carers who responded, were not entirely satisfied with social services.

In 2016/17 ERY had the 4th highest proportion of carers satisfied with social services, compared to the nearest 15 CIPFA neighbours (please see appendix, chart A3.37). Table 5.14.3 provides a summary of the results for this indicator from the past three surveys.

Table 5.14.3 Percentage of carers satisfied with social services. ERY compared to region and England (where results are available). Source: PHE

Period	ERY %	Yorkshire and the Humber %	England %
2012/13	51.7%	44.2%	43.1%
2014/15	45.9%	43.0%	41.2%
2016/17	43.1%	41.3%	39.0%

Analysis of the record level data found that 47.3% of rural carers in ERY were either extremely satisfied or very satisfied with social services over the past 12 months, in contrast to urban carers at 40.6%.



In contrast to the 43.1% who stated that they were either 'extremely satisfied' or 'very satisfied' with social services, 11.5% (n=42) stated that they were either quite, very or extremely dissatisfied. A comparison of urban and rural areas voicing dissatisfaction (using the 3 dissatisfied categories) found that they didn't have dissimilar results (11.8% and 10.7% respectively), although numbers were reasonably small (25 and 16 respectively).

5.14.4 Proportion of carers who report that they have been included or consulted in discussion about the person they care for

Nationally (and within ERY) there is a desire for the carer to be seen as an equal partner in the planning and delivery of care for the cared for person. By putting this into practice, it is widely considered that the risk of care arrangements breaking down are reduced and also provides better outcomes for both carer and cared for person.

This particular indicator reflects the carers experience of whether they believe they have had appropriate levels of consultation with social care and NHS services, about the person they care for. Question 18 of the SACE asked carers, "in the last 12 months, do you feel you have been involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for?" In 2016/17 the percent of ERY carers who answered "I always felt involved or consulted" and "I usually felt involved or consulted" equated to 74%. This was a reduction on the 76.4% in 2014/15, which in turn was a reduction from the 82% reported in 2012/13. The latest years results for ERY, are however higher than both regional and national averages.

Table 5.14.4 provides a comparison of ERY with region and England and in all periods ERY had a higher percent of carers who believed they had been included and consulted with services. In the first period (2012/13) the ERY percent was significantly higher than both the comparator values but by 2014/15 the ERY percent was classed as similar. Comparison with the nearest 15 CIPFA neighbours (chart A3.38 in the appendix) shows ERY to have the 6th highest local authority value in 2016/17.

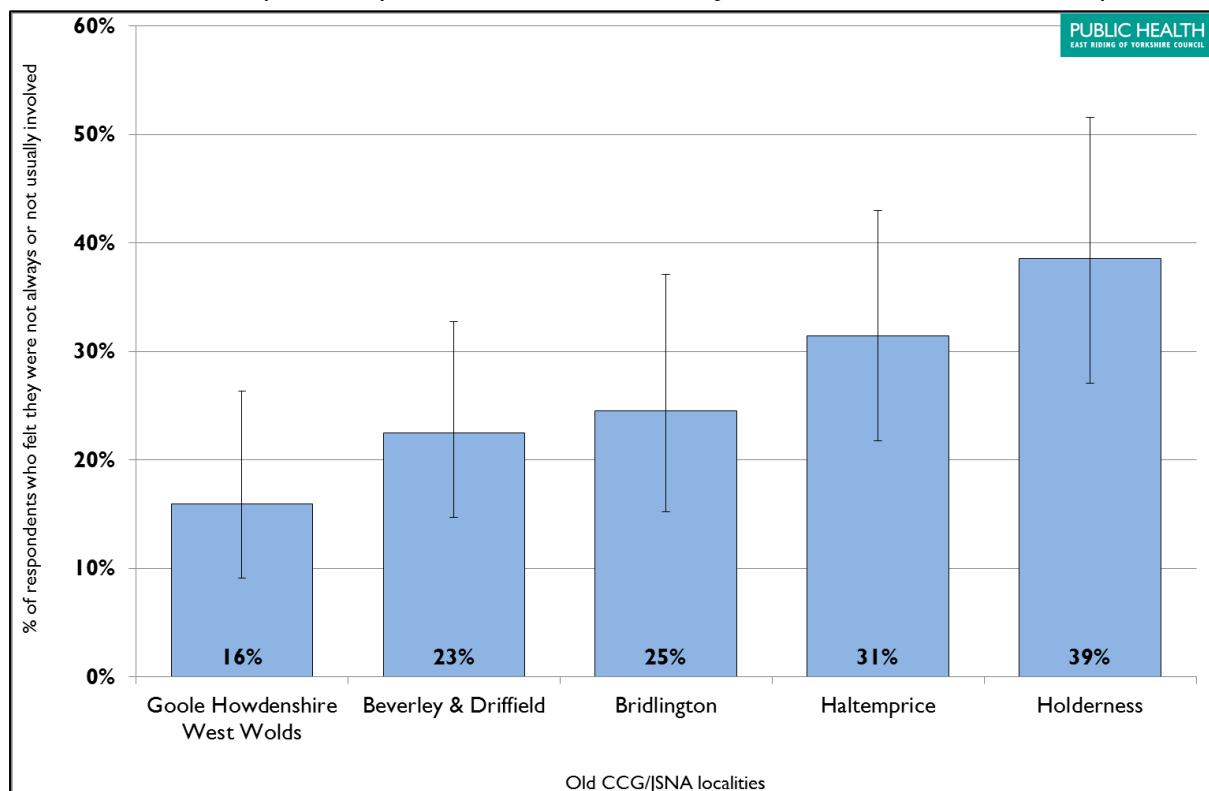
Table 5.14.4 Proportion of carers who report that they have been included or consulted in discussion about the person they care for. ERY compared to region and England. Source: PHE

Period	ERY %	Yorkshire and the Humber %	England %
2012/13	82.0%	75.5%	73.3%
2014/15	76.4%	74.6%	72.3%
2016/17	74.0%	73.6%	70.6%

The 2016/17 survey found that approximately 1 in 4 (26%) ERY carers *did not* always or didn't usually feel they were involved/consulted about the support and services provided to the person they care for. The prevalence of this response varied throughout the different communities of ERY. Results for individual wards were based on very small numbers and so instead a comparison of the old localities was once again used. Chart 5.14.6 shows the significant difference between residents in the Holderness area (39% of whom stated that they did not always or didn't usually feel consulted, this is the equivalent to over 1 in 3 carers) and Goole, Howdenshire and West Wolds (16%).



Chart 5.14.6 Percent of carers who report that they had not always or not usually been included or consulted in discussion about the person they care for. 2016/17. Old CCG/JSNA localities. Source: SACE survey



5.14.5 The proportion of carers who find it easy to find information about services

Gaining access to the appropriate information that carers need, not only benefits the carer but also the people they care for. Ensuring this information is easily accessible ensures there is a greater choice and enables the carer and cared for person to have greater control over their lives.

Question 16 of the survey asked carers “in the past year, have you generally found it easy or difficult to find information and advice about support, services or benefits?” In 2016/17, 69.4%* of ERY carers responded that information was “easy to find” or “fairly easy to find”, higher (but not significantly) than both regional and England averages. The 2016/17 ERY result was a reduction from the 72.9% reported by ERY carers in 2014/15, although in this earlier survey the ERY percentage was still higher than both the regional and England averages. However this could still be viewed that almost 3 out of 10 ERY carers who responded to the survey, could not easily find information about services. Table 5.14.7 summarises the information for both periods. Compared to the CIPFA neighbours (chart A3.39 in the appendix) ERY had the 6th highest value in 2016/17, compared to the other 15 local authorities.

However despite these seemingly positive results, qualitative research and feedback to services in the ERY found that many carers were still struggling to find adequate sources of information and in one place. The Carers Advisory Group believe that those carers already in contact with local authority services have a better chance of successfully accessing information about services. In contrast it is believed that those carers who have not identified themselves as carers, will struggle to easily find the appropriate information.



Table 5.14.7 The proportion of carers who find it easy to find information about services. ERY compared to region and England. Source: PHE

Period	ERY %	Yorkshire and the Humber %	England %
2014/15	72.9%	68.3%	66.0%
2016/17	69.4%*	66.3%*	64.2%

*rounding issues may show some variation (by 0.1%) between what is reported nationally for ERY and the local data set findings in section 6.2 of this document.

Analysis of the ERY SACE dataset did not find any major differences in where people lived and their ability to easily access information.

5.14.6 Discharge from hospital (national perspective)

At the time of writing there was no *quantitative* information made available at an ERY level regarding carers experiences of patients being discharged from hospital, however Carers UK (2017) provided a national perspective from their survey.

The majority of carers, who had experience of a hospital discharge during the previous year, stated that they either were not consulted about the discharge or were only consulted at the last minute. Carers often felt that patients were released too early from hospital and were not ready to come home, as a result patients were readmitted to hospital within a few months. In contrast there were a number of patients who stayed in hospital longer than needed, due to no sufficient support in the community being available.

This reinforces the concern that many carers feel they are not listened to and are therefore not made to feel part of the 'care team' of the person they are caring for.

5.14.7 Practical support (national perspective)

This section, like the previous one, uses information gathered from Carers UK (2017).

Almost 1 in 4 carers revealed they had no practical support to assist them in their caring role. The most common form of support was equipment for the home, mainly hoists, grab rails and grip handles. Other forms of support include help from family and friends and technology such as sensors or remote monitoring. The group of carers least likely to receive support were sandwich carers, who were bringing up a child as well as caring for someone else. Over recent years, the Carers Survey has discovered a reduction in the service provision with no alternative options provided. Out of those carers who received a direct payment from local authorities to help pay for care and support services, 46% stated they did not feel in control over the services they were offered, whilst 12% revealed they had no choice at all.



6. Survey of Adult Carers 2016-17: summary of results by the Adults Performance Team (Resource Strategy)

6.1 Section introduction by Public Health

The Survey of Adult Carers in England (SACE) is a biennial survey conducted in every local authority in England. To date the survey has been conducted on three separate occasions and was developed to find out if the services received by carers are actually helping them in their caring role. The survey also hoped to gain insights into the carers life outside of caring and their opinion about the services provided to the person they care for. Section 5 has already utilised some information sourced from the SACE survey, mainly where it was logical to do so, such as tying in the health of carers and the cared for person (see 5.12) or interaction with services (see 5.14). The rest of section 6 has been written by ERY Council's Adults Performance Team and again highlights some of the key indicators reported from the survey, alongside the results of a number of other questions.

6.2 Summary

The East Riding of Yorkshire Council survey had the second highest response rate in the region and one of only six nationally to achieve a response rate of over 60%. This reflects the effort put into running the survey and the overall engagement with carers.

The Survey of Adult Carers in England, 2016-17 (SACE) has produced a positive set of results for East Riding of Yorkshire Council with all being above regional and England averages. Compared to the previous survey the ERYC results have decreased in all but one ASCOF indicator. However, these decreases are minimal in comparison to the statistical confidence threshold. The table below shows the ASCOF results from the last three surveys that have taken place and also provides a direction of travel (DoT) comparing 2016/17 results to 2014/15 results and also 2016/17 results to 2012/13 results.

Table 6.1 Key ASCOF Indicators. Source: ERYC Adults Performance Team

Ref	ASCOF Indicator	12/13	14/15	16/17	DoT (compar ed to 14/15)	DoT (compar ed to 12/13)	Y & H Average (16/17)	England Average (16/17)
ID	Carer reported quality of life (score out of 12)	8.4	8.2	8.1	↓	↓	8.0	7.7
11(2)	Proportion of carers who reported that they had as much social contact as they would like	-	39.7	40.6	↑	-	38.7	35.5
3B	Overall satisfaction of carers with social services	51.7	45.9	43.2	↓	↓	41.3	39.0
3C	The proportion of carers who report that they have been included or consulted in discussions about the person they care for	82.0	76.4	74.0	↓	↓	73.6	70.6
3D(2)	The proportion of carers who find it easy to find information about services	-	72.9	69.5	↓	-	66.4	64.2



6.3 Background

This report provides a commentary relating to East Riding of Yorkshire Council on the published findings from the Survey of Adult Carers in England, 2016-17 (SACE). The survey has the status of an Official Statistics publication.

Councils with Adult Social Services Responsibilities (CASSRs) are required to survey unpaid adult carers who care for an adult every other year. Responses aim to reflect the quality of life and experience of social care over the previous year, covering support provided by voluntary organisations, private agencies or social services.

The survey collects information on:-

- The carer and their role
- Satisfaction with the support or services received from social services
- Social contact and isolation
- How easy it is to find information about support
- The support or services provided to the person cared for
- Carer Reported Quality of Life Score

The survey is posted to a representative sample of unpaid carers (the eligible population being determined in summer 2016, the survey was conducted in autumn 2016 and returns submitted to NHS Digital by 28th February 2017.). This year's national survey included 55,700 responses across 151 councils. Councils are required to select a sample such that the survey results have a margin of error of less than five percentage points.

Previously only carers who had a social care assessment or review in the last 12 months were surveyed. To reflect councils' duties under the Care Act (2014) to ensure relevant information and advice are made available to carers the criteria for inclusion in the survey has changed so that carers provided with advice and information but who did not have a review or assessment are eligible. Some councils reported having minimal information on carers who did not receive a review or assessment so carers from this group were not able to be included in their sample. The East Riding of Yorkshire Council survey included all carers registered with the council.

6.4 National (England) Headlines

For England the average ASCOF "carer reported quality of life" score is 7.7. The national commentary noted that carers who had a quality of life score lower than the national average are more likely to spend 50 hours a week or more on their caring responsibilities.

The national press release highlighted the finding that financial problems caused by caring were linked to increased feelings of social isolation.

Almost 40 % of carers who reported the most serious financial difficulties also felt socially isolated. For carers who reported not having financial problems caused by their caring duties (54 %), almost 10 % felt socially isolated.

Financial difficulties caused by caring responsibilities was the only variable found to have a statistically significant effect on every question analysed in the national report.



Without seeking to minimise the issue of financial difficulties it is only a minority of respondents who report significant financial issues.

Table 6.2 Question 15 - In the last 12 months, has caring caused you any financial difficulties? Source: ERYC Adults Performance Team

	No, not at all	Yes, to some extent	Yes, a lot
ERYC	58.6	32.6	8.8
England	54.4	36.0	9.6

Table 6.3 Source: ERYC Adults Performance Team

Key Facts – England and ERYC comparison	England	ERYC
Of carers who received support or services satisfaction with the support or services they received:-		
• extremely, very or quite satisfied	71%	75%
• extremely, very or quite dissatisfied	13%	11%
Percentage of carers who spend more than 35 hours per week providing care.	59%	57%
100 hours per week providing care	36%	33%
Percentage of carers who have been providing unpaid care for over 20 years.	21%	20%
Percentage of all carers who as a result of their caring role report 'feeling tired'	76%	74%
Experiencing 'disturbed sleep'.	64%	62%

6.5 Analysis of East Riding of Yorkshire Council survey

The carer is asked to describe the cared for person “as having”. The survey does not ask for a medical description. The East Riding responses differ from the England average with lower proportion of “dementia”, fewer “learning disability or difficulty” but more described as a long standing illness. The respondent could select more than one item (i.e. unlike the Primary Support Reason).

Table 6.4 Source: ERYC Adults Performance Team

The cared for person is described as having	ERYC %	England %
Dementia	23.4	35.1
A physical disability	58.2	53.1
Sight or hearing loss	31.8	30.2
A mental health problem	23.3	20.5
Problems connected to ageing	34.5	35.2
A learning disability or difficulty	14.9	19.3
Long-standing illness	50.9	40.0
Terminal illness	6.8	5.2
Alcohol or drug dependency	1.2	1.6



East Riding survey indicates:

- More carers live with the person they care for (85%) compared to the England average (75%).
- More carers are retired (66.5%) than the England average (57.8%).
- Less carers in employment or self-employed (17.4% to 23.8%).
- More carers with no children under 18 (90% to 83%).

Some responses for the East Riding are similar to the England average:

- 68% have been helping the cared for person for over five years.
- 33% spend more than 100 hours per week helping the person they care for.
- 14% state they have no control over their daily life
- 15% feel they have little social contact with people and feel socially isolated
- 70% of those who had sought information and advice about support, services or benefits in the last 12 months though it was very or fairly easy to find.
- 87% found the information very or quite helpful.
- 74% reported they had been involved or consulted as much as they wanted to be, in discussions about the support or services provided to the cared for person.

The type of support provided by carers in the East Riding is similar to the England average (see table 6.5).

Table 6.5 Source: ERYC Adults Performance Team

Type of support provided	ERYC	England
Other practical help	96.1	92.6
Keeping an eye on him/her to see he/she is all right	90.9	90.6
Giving emotional support	82.8	84.1
Helping with paperwork or financial matters	80.6	85.3
Helping with dealing with care services and benefits	80.4	85.2
Keeping him/her company	79.2	82.5
Giving medicines	77.9	76
Taking him/her out	77.8	76
Personal care	69.9	68.8
Physical help	62.2	58.2
Other help	17.2	16.7

The appendix (section Appendix 4) features further information relating to section 6 of this document.



7. Carers stories: The Caring Experience – The Reality in the East Riding of Yorkshire

7.1 Section introduction by Public Health

Section 7 has been written by Rachel Trees, a PhD student with the University of Hull. It was originally written as a report and was produced in collaboration with the East Riding Carers Advisory Group.

The author lists the following as the key findings and areas for consideration:

- Training and education opportunities
- Coping mechanisms
- Formal care and other services (including respite care)
- Relationships with others
- Relationship between carer and carer and cared for
- Competing care demands
- Concerns for the future
- Loss of the 'Old Life'

7.2 Introduction

Public Health England (PHE) published their “Recent Trends in Life Expectancy at Older Ages” report on 12th February 2016. This report confirmed that in the UK, death rates have steadily declined over recent decades and that in 2014, 55% of all deaths in England occurred in people over the age of 80 years (PHE 2016). The report also showed increased average life expectancy of those aged 65 from 13 years in 1981 to 19 years in 2014 in males and from 17 years to 21 years in females.

Healthy life expectancy however, is not keeping pace with increased life expectancy. This results in a greater number of elderly citizens suffering from chronic illnesses which require some level of social care. This care can be as simple as assistance with transport to attend appointments or as intensive as 24 hours 1:1 care.

Population Demographics in the UK are also changing – divorce rates are increasing and the Office for National Statistics report that in 2012 42% of marriages ended in divorce in England and Wales. Informal caring has historically been largely provided by the spouse. High divorce rates mean that this may not necessarily be the case and some researchers have suggested that divorce results in the fracturing of families, resulting in a less cohesive family unit which may be less likely to provide informal care. Birth rates continue to fall in the UK which results in fewer offspring who may provide informal care to parents in later life.

The increasingly elderly and infirm population of the UK has serious consequences in terms of increasing formal care demands which are currently failing to be met. It is imperative therefore that informal care options are utilised to fill the gap of care need.

There are around 6.5 million informal carers in the UK and this is expected to increase by 40% by 2037 (Carers UK 2015). In reality, this number is likely to be much higher, as carers often do not identify themselves as such for a variety of reasons.



The informal carer provides an invaluable service – a service which could not be sustained via formal care routes. Unfortunately informal carers' experiences, problems and needs are not well understood in our area and individual carers' experiences, thoughts and opinions have never been sought. This report attempts to remedy this.

In summary, the 'caring problem' is set to continue with increasing impact into the future. Carers experiences – their own stories, are often unheard by the Policy makers who may be considered too far removed from the reality of the situation to truly understand the complex informal caring issue. This report hopes to address this through the presentation of the real carer experience.

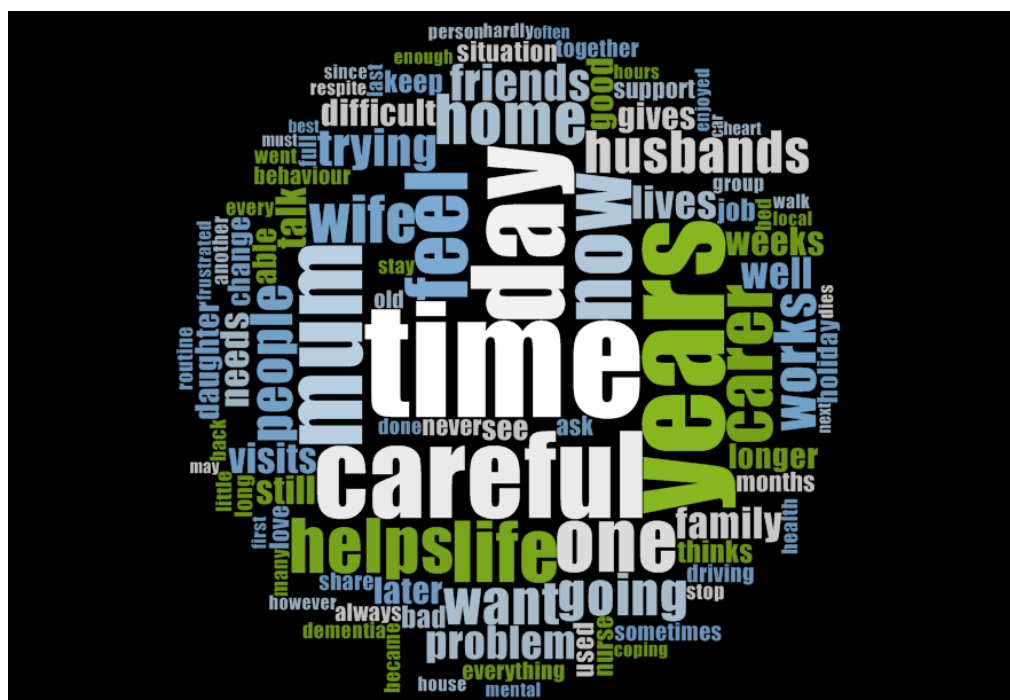
A call for carers to submit their stories to the Carers Advisory Group was made in the East Riding Newsletter. The advert called for carers to come forward and reveal how being a carer has impacted their life – what life was like before and how it is now, what caring has stopped them doing, what do they have to now take responsibility for, how they feel about their role, how do they cope, what support do they get from others, who do they speak to about it.

A total of 14 responses were received from carers in a number of different circumstances, caring for a variety of individuals. The stories told in these statements were heartfelt, moving and at times harrowing and extremely concerning.

The word cloud below summarises the words said most often throughout the statements, increasing in size according to the number of times they were mentioned. This provides a visual summary of the issues of those carers. The next section of the report provides a summary of each theme identified with a number of quotations from the carers to provide clarity and evidential weight to the problems highlighted.

The report concludes with a summary of the issues identified for further consideration and deliberation.

7.3 Word Cloud



The word cloud is a representational summary of the statements provided by the carers of East Yorkshire. It is clear to see that the words “time”, “years”, “day”, “careful”, “now”, “feel” and “life” appear most frequently in the carer statements.

It is also interesting to note that the word “frustration” appeared in the statements of 64% of respondents, and “love” in 93% of statements.

7.4 Findings

7.4.1 Training and Education opportunities

A major concern of the carers was that they felt unprepared, unready and unskilled in the caring role which many felt had been forced upon them. The quotations below demonstrate some of the carers’ feelings of concern and inadequacy:

Doing it without knowledge makes it hard

Having no previous experience or knowledge, her difficult behaviour has tested us

Were we qualified to be carers? - No

We just had to start on day 1 and learn on the job, day by day

We never chose to be in this position and we certainly never trained for it, yet here we are

Life very quickly becomes a steep learning curve

Other carers have found opportunities for some learning which they have found useful:

I attended the Dementia champion’s course so I could gain more knowledge about the disease, putting myself in a position to help support both [wife] and others by preparing and delivering dementia presentations

A seven week course providing basic information but most of all, people who will talk and talk and talk about it. It is so effective, I do it again 3 years later.

Other carers clearly find getting assistance more problematic:

I have tried to find some help / manual / users guide / instruction book. I have contacted and subscribed to a number of help societies, clubs, memory cafes etc. But, with the best will in the world, these seem short in the areas that I am deficient in.

I appreciate that my suggestion of a manual or users guide is fanciful but is there anything that might remotely somehow help?

7.4.2 Coping Mechanisms

The carer statements revealed the struggle that many carers face on a daily basis. Methods for coping with the demands of caring were shared within the statements, particularly demonstrating the importance work, friends, self-talk and of the local Carers Group meetings as an opportunity for



social engagement but also for support, friendship and education. One respondent also identified technological solutions for coping, such as CCTV.

My wife's intended winding down towards retiring from her mobile hairdressing business is on hold because it provides relief from the pressure

[Wife] who had to go out for the evening to calm down

I tend to go for a walk or round to a neighbour's just to get away for a while

I am fortunate to have found a friend although not local has been a rock to me, and kept my spirit up when I have found things hard going. We talk on the internet and on Skype

After I have put [wife] to bed at night I have my me time. I settle down with a glass of wine and watch a film, listen to music or just reflect on the day's events

I try to talk to myself and say that my behaviour is unacceptable and that it's not his fault and I will try harder

When things get on top of me there's nowhere I can go to get away

My husband tends to shout and swear

Having a good old cry and taking to our beds also happens

The CCTV in her room (accessed via my fancy phone) minimises the anxiety around leaving her

I found out about the Carers drop in group and went along and I have never regretted my decision. It took a lot to walk through the door but the help and support I received was like a breath of fresh air. I have friends I can talk to when times are tough and I began to feel like a person in my own right.

I started to attend the Pocklington carers Group a year ago after a friend in the same position introduced me to the group. It has been very useful, informing me of what help is available as well as a chance to be with other people in the same situation

I attend meetings with carers in Pocklington and Market Weighton

I like to go to my local carer's group because I know that although we may have differing caring roles I will be able to get a welcome and a friendly ear.

7.4.3 Formal Care and Other Services

The carers highlighted issues regarding poor respite care – the cost, availability and quality of the care available and the added worry this places on an already stressful situation. They also identified frustration with other services such as the NHS and social Services, and the lack of understanding the 'experts' had. Communication failures seem to be a key theme- lack of understanding regarding what input carers could expect. There also seems to be concern regarding the longevity of input from services – initial 'promises' fading away to nothing in due course:

We do get respite but it is not always when you need it - Having to book ahead months in advance



Not being able to put my wife in respite as she will not get the same level of care she gets at home, despite the high prices they charge.

The same thing when I put her in respite for a week, which was very hard to do in the first place. Again, not willing to keep her mobility with help due to the same reason, health and safety, so I will not put her in respite again, which does not give me a break.

Our Age Concern carers are having more difficulty and we are getting demoralised again

Time and again in the difficult years and you ask for help from the 'experts', and they say to you "well you know more than we do", that isn't just discouraging, it is devastating

When there purports to be a mental health team whose remit mum falls into, but whose policy is to ignore dementia sufferers because they 'haven't the time'

When her 6 monthly reviews with the consultant cease immediately her scores on the mini-mental test fall below a certain level and without explanation other than to say "I cannot see her anymore", that feels like abandonment.

Early days are spent introducing the various services to her but they fade away after the initial promise

Sadly pounds and pence rule this world and caring for ones fellow man comes very low down any list of priorities

It is a fact of life that if all the unpaid carers were to stop caring the whole system would come to an abrupt standstill.

[One] would never for one minute consider withdrawing from their caring role. So sadly they continue to be used, abused and seldom listened to

[I] have little confidence in the system as it is at the moment

[I am} slightly resentful that the authorities don't care, they just expect me to get on with it and save them money

The NHS does not help ... another case of authority not caring in that they do not employ enough people to do the job.

7.4.4 Relationships with Others

A further area of concern for carers is their relationship with others. Involvement of other family members in the caring role varies greatly from case to case, however it is clear that no matter what the level of involvement of others, the carer still carries the full weight of responsibility for the person they care for. Carers express their frustration that other family members do not take an active role and it is important to consider that the intensity of the caring role often allows little time to maintain contacts with family and friends and often has a detrimental effect on existing familial relationships:

My granddaughter helps with this but my husband resents the relationship we have and is jealous of the attention I give her



My younger son gives as much support as he is able to as a listener rather than practical but he has his own family problems to deal with

I hope to share this with my sister but her often repeated mantra to both me and our mother is "I only have one day off and I want to spend it with my husband".

The amount of time I am spending with Mum makes her look to me more and more. This creates jealousy from my sister

I have tested my wife [in caring for my Mother] more than I should have. We have had many a 'last chance'.

Not getting much support from family or friends as they could not manage my wife on their own.

As to help from family or friends, my brother lives 250 miles away so can't do anything, my wife's brother and family live 70 miles away. The rest of our families are dead and due to not getting out I no longer have any friends

Friends and even family rarely come to see [wife].

Who is going to look after him? Not his 3 children from a previous marriage who have lives of their own and Dad isn't part of it!

As a carer I don't think that family members understand what I have to put up with in caring for my wife

7.4.5 Relationship between carer and carer and cared for

The carers have highlighted the changing relationship between the carer and cared for. Sometimes the trials of caring have highlighted the strengths of a relationship, but very often, the relationship has been changed to the detriment. There is a great sense of sadness and grief that the relationship loses its old position (husband and wife, Father and daughter etc.) and becomes that of carer and cared for. Many of the carers found this extremely upsetting and made links back to how their lives used to be. Statements also showed differences in the carers' interpretation of the situation – whether they cared for reasons of genuine love and affection or through feelings of duty and obligation, it was interesting to see these differences:

We are no longer affectionate towards one another, we cannot share a joke, we cannot talk in any meaningful way and we no longer have a physical relationship

My former close companion, good friend and constant support, my lover and beloved has become my dependent child

Her behaviour has corroded our feelings

They are not the same person you married and are as unhappy with the situation as you are. It does not make easy bedfellows.

We are not 'husband and wife' now

There are days I could gladly walk away and let him get on with it

Here we are, unable through our moral consciences or love to do anything other than care.



My feelings towards my husband are now that of a carer and at times I feel like I am living with a child and not someone I used to be able to talk to and discuss day to day problems with.

He doesn't care about me or my feelings, why should I bother? If I do, who is going to look after him?

Our relationship altered beyond all recognition. I feel that I am looking after a stranger and that my husband has gone

She has pushed us to our limits and only duty has kept us going

The decisions, eventually must be mine alone, for better or worse

Ultimately the buck stops with me and sometimes it can be a little frightening

Although our relationship has changed due to dementia it remains strong

So long as we can remain together and share our love for each other then I shall feel life hasn't been all bad

Having battled through the hard times and been enthralled by the good times, I know that this is the best thing I have ever done

I don't think that family members understand what I have to put up with in caring for my wife who I love dearly.

The majority of carers do it out of love and duty

I am lucky in that I married an amazing woman and our trials and tribulations have not affected our relationship at all, we are still very much in love after 42 years of marriage.

Saying that I would not change a thing, even though it is hard work looking after her

She is my whole life

Did I love my husband? Yes of course I did and I do not regret one day I looked after him

I promised him I would look after him at home and not put him into care but even though I had help, I still found it hard work

We have a strong marriage and that helps my caring role

How can you not do it?

She expected me to look after her and how could I not do so?

Forty four years ago I stood in Church before God, the Minister and my family I made promises, one of which was to stand by my husband in sickness and in health

I would never think of leaving him as I have heard other people have done in similar situations.



7.4.6 Competing care demands

Often carers are responsible for providing care for more than one individual. This often provides additional worry and concerns as the carer attempts to split themselves fairly between care recipients, attempts to manage multiple caring relationships and carry out the duties involved in each. Competing care demands can have an extremely detrimental effect on the carer:

My husband was taken ill this year and whilst he was in hospital and recuperating I found life pretty difficult - sorting care for her [daughter] and trying to visit hospital

My daughter has mental health problems so I also have to be there for her too. These two situations often conflict

I also have 2 elderly parents in their late 80's who also need my help most days for one reason or another and there is only me and I'm trying to split my time between the 3 of them

7.4.7 Concerns for the future

One of the biggest worries the carers have expressed is the worry about future care – whether that is the increasing needs of the cared for, or the worry of absence of the carer for a number of reasons such as ill health. It seems carers often feel that they are managing the current situation and continue to do so, as long as no changes occur to upset the systems and process they have put in place. Illness, competing demands and changes to their situation all cause great stress and worry for carers. It is also obvious that carers feel required, or even forced, to put their own needs and requirements below those of the person(s) they care for:

It would be devastating for both of us if I couldn't carry on looking after him

My husband and I are now both pensioners and know that the next few years will be thinking about what happens when we can no longer care for her

It has brought it home to me that I could not look after her on my own and I cry for her

I dread to think of the future and what I may have to do

I worry that at some point he may need full time care. I am not being selfish but will I be able to do it? I don't know

The thing I am most scared of is, if something happened to me, who would look after my wife?

What I can do to look after my own physical and mental health?

I have to carry on regardless - even if I feel unwell myself

Everything is a worry as far as managing if I am ill and day to day situations, my health and my life is very much on hold

I am unable to take exercise to look after my physical needs and my mental state is deteriorating.

My health began to suffer as I was diagnosed with cancer which involved surgery and a year of chemotherapy and radiotherapy. I was still caring for my husband but on my bad days managed to get extra



help. This was followed 5 years later with a knee replacement which I found difficult to manage both my treatment and care at the same time.

I never bothered too much about my appearance, throwing on a pair of jeans and a T shirt - what was the point in dressing up, who was going to notice?

I am not allowed to be sick or feel like staying in bed for an extra hour or so because I am expected to be at their beck and call - no one gives any thought to how I might be feeling or if I am having a rough day

7.4.8 Loss of the 'Old Life'

One of the biggest 'losses' to carers is that their life is irrevocably changed through the demands of caring. Often this results in no longer being able to sustain formal employment which also impacts on the financial income of the household, the opportunity for social interactions and communication and the opportunity to 'escape' the caring role for a while. Further loss of social interactions occur as well, such as going out with friends, maintaining hobbies, going on holiday and ultimately living the life they expected to lead. The pressures of caring also result in some personality changes of the carers – changes they find difficult to admit to and accept going forward. Other changes include the redistribution of household tasks such as cooking and cleaning. Often the carer feels overwhelmed by the duties they are now expected to carry out alone, ill-prepared and isolated:

I have discovered at nearly 70 years old that I have a bad temper - I never thought I had. I was always laid back and happy

Often it is like having 2 people arguing in my head, one of them saying cruel things and the other explaining that it isn't my husband's fault

Have I become a different person since my daughter was born? Absolutely. As you will gather being a carer has made me very intolerant!

Am I cynical? Wow am !!!!!.

Every time the flashes of guilt I feel at my own impatience and inadequacy to deal with the situation rises to the surface but I am unable to relinquish my hold on my sometimes ferocious anger, shame and guilt at my behaviour

Where once I was quite and outgoing confident person, I became withdrawn and less confident

[I am] a long way from the confident, self-assured successful, happy PA!

My level of tolerance seems very low

Until this point we had a full social life which involved us being together for some activities and separate for others

We went out with friends to our local every Saturday evening and regularly went out for a meal

We were in the happy position of being able to make the most of any opportunities that arose

Doing things on my own or with my granddaughter need careful planning and organisation so that someone is with him



He cannot be left alone for much more than half an hour

We cannot plan outings etc. anymore

Until the time that my husband developed the early symptoms of vascular dementia our lives were very full

We travelled extensively with two holidays abroad each year as well as short breaks, visiting family and friends.

On the home front we shared all the jobs in the house - cleaning cooking, preparing and freezing garden produce, choosing and buying furniture and furnishings when required

Wherever we went we shared the driving, making long distance journeys easier

All our financial arrangements, savings and investments as well as all major expenditure were discussed and agreed between us

Visits to the theatre or cinema, meals with friends and family were regular items in our diary and we enjoyed the local pub quiz each week.

Nowadays we seldom go more than a couple of miles from the house on our own

With the best will in the world, looking after a dependant adult is time consuming

Taking over control of our money has been a sharp learning curve for me

Only one of us can be employed at a time which had an impact on our finances

We can never just do as we please because her needs are always first

When we are invited out, nearly always one of us goes and the other stays at home

All responsibilities are now for me to do,

Before my wife became so ill we had a narrow boat on the canals which we loved dearly.

We used to go out to the pub occasionally and go shopping together and occasionally go for a run out in the car just to get out of the house. Now the only time we get out of the house is either for medical or dental appointments

Now I do everything around the house, cooking, cleaning, laundry and accounts.

We had a very good social life, regularly going to work functions. A group of 8 to 10 of us would go to the theatre every month. We also met up with a group of friends every 3 weeks for a meal and went out most Sundays for lunch

Over the past few years we have stopped going to the theatre, don't go out with friends anymore

We stopped going on holidays. I stopped taking [wife] to restaurants and cafes.

As his condition got worse it meant that I had to take over most jobs in the house. I was working full time but that became impractical so I gave the job up.



It also meant our finances took a big hit

We've been together 25 years and I try to remember how things used to be and the fact that we did everything together and enjoyed each other's company.

Before I became a carer I had a fantastic job and had reached a position that I had worked for a very long time to achieve

We used to get out most weekends to Boule competitions throughout the UK and the social events that went with it. We had to stop going and we seemed to be spending more time at home hardly seeing anybody. I eventually had to give up my job and I felt very bitter about that, the rug had been pulled on my career and it had nothing to do with me!

We are no longer able to enjoy many things that we took for granted and looked forward to enjoying more after retirement, particularly travel

There are many things which I cannot easily do... One of these is simply to talk about the situation.

sometimes I would like to just talk to someone, laugh about the funny aspects of the situation, have someone understand the heartache and loneliness I feel at not being able to share things (TV programmes, political issues, world events, local news).

Again, it is communication that I miss so much

In the real world, "How's your Mum?" is as much as you get before they glaze over and rush off. My guess is embarrassment from recognising they don't want to do the same. Their willingness to offer excuses kind of gives it away

I am mostly on my own

I do not feel comfortable leaving her to go out of an evening

When I feel the need to talk to someone I am stuck, because I only have my wife to talk to and I can't put my problems on her and she has enough problems of her own

Over the past few years we have stopped going to the theatre, don't go out with friends anymore

Friends and even family rarely come to see [wife]. Our social life is just about non-existent

I can't say that that I enjoyed it [giving up employment], I missed the camaraderie of my fellow workers

He had to stop driving and as I do not drive this had quite an effect on our lives. We stopped going on holiday, out socially and apart from work I felt trapped by 4 walls.

During this time my son from a previous marriage passed away aged 25. I felt like my world had collapsed around my ears. I had no one to talk to anymore.



7.5 Key Areas for Consideration

The responses from carers have shown the first-hand experiences of carers in our area – what concerns them, how they feel, what they miss and what they do. This page summarises the carer opinions and suggests areas that may be considered in future plans in an attempt to improve the experience, indeed the lives of carers and the people they care for.

1. Education and training opportunities for carers

Formal courses, helplines, directory of services etc.

2. Coping mechanisms

Opportunities for distance – for carers to remove themselves from the caring situation for a short period are not always possible. Potential for technological methods to assist in managing this. Availability of someone to talk to – helplines, Carer's support meetings etc.

3. Shortcomings of formal services

Respite care availability, quality and cost concerns. Volunteer services and charities communication regarding expectations and actual remit – clarity in what can be expected from these organisations as well as NHS and Social Care.

4. Relationships

Multiple caring roles create extra pressure on carers. Caring roles affect the wider family unit – not just those doing the caring. Carers feeling isolated and losing touch with friends and family due to the restrictions imposed by caring. The relationship between carer and cared for can replace the existing relationship e.g. 'husband and wife' leading to feelings of grief, guilt, frustration, duty and obligation.

5. Concerns for the future

Who will provide the care if I am unable to. Carers cannot take adequate care of themselves as the needs of others must come first.

6. Loss of the 'old life'

Financial implications of giving up paid employment to care. Lack of opportunities for social interactions – importance of communication and engagement opportunities such as Carers Groups. Grief for previous life and forced adoption of new roles in the house such as cooking and financial management – the pressure of increased responsibility. Severity of caring pressure results in personality changes of carers towards anger, frustration, lack of confidence etc.



8. Stakeholder views (including focus on specific providers and commissioners)

8.1 Section introduction

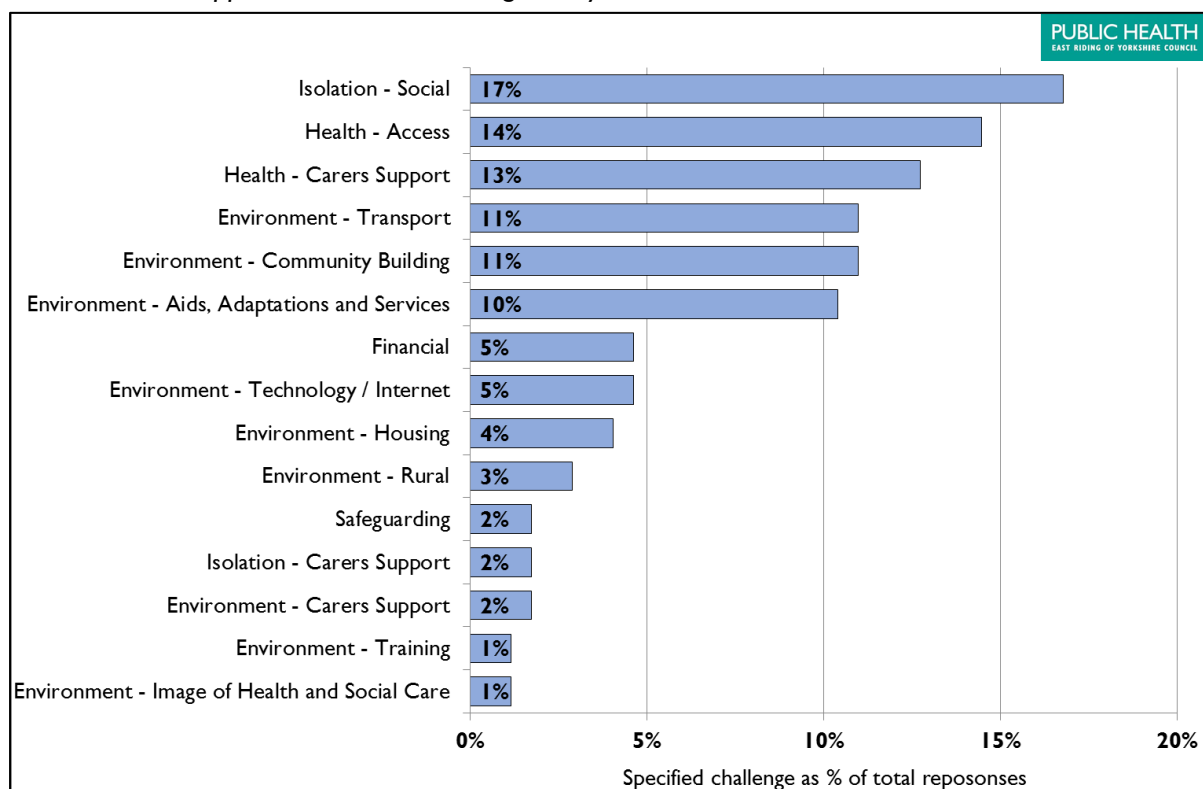
This section aims to compile the opinions about carer's needs and challenges, gained from stakeholders attending the Carers Rights day. It also provides an opportunity for local providers and commissioners to highlight how they are working with carers and the persons they care for.

8.2 Stakeholder views from the Carer Rights Day (Building Carer Friendly Communities)

In November 2016 a multi-agency stakeholder event called 'Carer Rights Day – Building Carer Friendly Communities' was held in Driffield, featuring presentations and workshops. In attendance were East Riding of Yorkshire Council, Carer's Advisory Group, NHS ERY CCG, NHS Humber Foundation Trust and many other organisations. Presentations were made by the different organisations, including one by the Public Health team and the Carer's Advisory Group with regard to JSNA. Table discussions allowed stakeholders to express their views on the needs of carers and were documented by facilitators.

A full detailed list can be found in table A5.2 in the appendix, however a summary of the views (grouped into overarching themes or 'challenges') can be found below. Chart 8.1 shows which of the challenges were raised most frequently by the stakeholders.

Chart 8.1 Challenges relating to carers identified by stakeholders, as % of all challenges raised. Also shown in table A5.1 in the appendix. Source: Carers Rights Day 2016



The top five challenges most frequently raised were:

1. Isolation – Social, which included:
 - a. access to support and shops
 - b. feeling isolated
 - c. living in rural areas
 - d. the loss of confidence and self-esteem
2. Health – Access, which included:
 - a. access to information
 - b. GP attitudes towards carers
 - c. services not always accessible due to mobility
3. Health – Carers Support, which included:
 - a. carers not looking after their own health and wellbeing
 - b. accessing the right support
 - c. impact on mental health and depression
4. Environment – Transport, which included:
 - a. rurality and transport issues/concerns
 - b. need to develop community transport
 - c. ability to travel to hospital
5. Environment – Community Building, which included:
 - a. awareness of what is already available in the community
 - b. difficulty finding information of what is available
 - c. lack of links between local services and main services

The event also produced a series of pledges from the stakeholders, regarding what they can do for carers. These pledges are provided in table A5.3 in the appendix.

8.3 Provider focus: Humber NHS Foundation Trust

8.3.1 Section introduction by Public Health

Section 8.3 has been written in its entirety by Humber NHS Foundation Trust and provides information about how the Trust liaises with carers and the services they provide.

8.3.2 Introduction

Humber NHS Foundation Trust (HFT) mainly provides services to the city of Hull and the East Riding of Yorkshire. A population of nearly 600,000 people living in urban, rural and coastal areas.

The Trust also provides some services to parts of north east Lincolnshire and north Yorkshire and some specialist services to people from other parts of the country.



Services are managed under four care groups:

- The Adult Mental Health Care Group
- The Children's and Learning Disability Care Group
- The Community Services and Older Peoples Mental Health Care Group
- The Specialist Services Care Group

Humber NHS Foundation Trust has developed a Patient and Carer Experience Strategy February 2016 – 2018. The aim of the strategy is to

'....develop a culture throughout the trust that places the quality of patient and carer experience at the heart of everything we do.'

To ensure patients and carers receive the best possible experience the strategy includes seven pledges which have been developed through consultation with patient and carer experience committees and patient and carer champions.

The seven pledges are as follows:

Pledge 1: We will listen to our patients and carers and respond to their feedback:

Pledge 2: We will provide a safe environment for our patients

Pledge 3: We will meet the physical and comfort needs of our patients

Pledge 4: We will support the carers of our patients **Pledge 5:** We will recognise our patients and carers individuality and involve them in decisions about their care

Pledge 6: We will communicate effectively with patients throughout their journey

Pledge 7: We will aim to ensure our patients are cared for by skilled and caring staff

8.3.2 What we are doing

Patients and carers are asked to complete the Friends and Family Test which enables them to comment on their experience. This information is collated by the trust and reported on.

During 2016 other initiatives have taken place to improve patient and carer experience.

It had been identified that we could improve how we collect real time feedback and because of this one care group completed a pilot of the Net Promotor model. This model is a way of enabling patients and carers to give real time feedback about their experience of the service. The outcome of this pilot is currently being reviewed but initial findings are positive.

As patients and carers had already told us that they do not always feel listened to or involved in their plan of care, we wanted to learn from this. A Carers Stories pilot commenced on one mental health inpatient treatment unit and this pilot very quickly led to the care group developing 'Service Offers'.

Service offers are much more than information leaflets although they do include information about the following:



- The Service
- The Team
- Treatment and interventions that the team provide
- How patients and carers can be involved in decision making about treatment options and care planning.
- How carers can be supported emotionally and practically

However service offers also describe our commitment to the patients and carers who use our services. It is hoped that by service users knowing and understanding what they can expect from the service they will be able to hold us to account if they feel we are not delivering on our commitments to them. This feedback will help us know why and what we need to improve.

One important part of the mental health inpatient Service Offer is the review of reception meetings which take place soon after a patient is admitted. This is an opportunity for the patient and carer to be given information about the service and team, to tell their story and be involved wherever possible in developing the patient's plan of care.

The reception meetings should ensure that patients and carers are listened to and are involved in decisions about their care. This level of communication and involvement should be ongoing throughout the patient's journey, for example when planning discharge from a mental health inpatient service and/or transition to a community mental health team.

Still on the theme of listening to and communicating with patients and carers one care group is launching 'Hello my name is...' which is a national campaign started by Dr Kate Granger who was diagnosed with terminal cancer and who became frustrated with the number of staff who did not introduce themselves to her when she was receiving treatment. The 'Hello my name is ...' campaign is not just about staff introducing themselves it is about providing compassionate care which starts with patients knowing who they are speaking to and who is providing their care. Following the launch and implementation of 'Hello my name is...' the teams are looking to regularly monitor the impact on patient and carer experience.

An invitation has been extended to patients and carers who access the community services in Whitby, North Yorkshire or the Older Peoples Mental Health service in Hull and East Riding to be part of our staff recruitment process. Working in partnership with patients and carers will strengthen our recruitment practice by helping staff recognise the value that is placed on patient and carer experience. Involving patients and carers in staff recruitment helps us know that our staff have the right qualities such as empathy and understanding.

As part of communicating effectively with patients and carers the trust will continue to monitor complaints and triangulate the information from complaints with information from the Friends and family test and incidents. This will help the trust understand what we are doing well and help identify the things we need to improve

8.3.3 In summary

The trust has undertaken several initiatives over the last twelve months to improve patient and carer experience but there is still work to be done.



Over the next twelve months the trust would like to further develop communication and joint work with other agencies.

We need to ensure that patient and carer experience is at the heart of everything we do and that staff are supported to do this. We need to ensure team training plans are completed and reviewed and good practice or learning is shared across the organisation.

The development of a Carers Charter and Patients Charter should be considered.

8.4 Provider focus: City Health Care Partnership (CHCP)

8.4.1 Section introduction by Public Health

Section 8.4 has been written by City Health Care Partnership (CHCP); it highlights the organisations involvement in raising awareness of carers support services and considers how best to support carers and how to better understand their specific needs.

8.4.2 City Health Care Partnership (CHCP)

CHCP are currently working in partnership with East Riding Carers Support Service to host a number of joint Hull and East Riding events aimed at raising awareness of carers support services. These include the following events:

- Living with Dementia- 26th April, 2017
- Celebrating Surviving Stroke event- 17th May 2017
- East Riding Carers Support Service Annual Carer Conference- 13th June 2017
- Learning Disability Awareness- February 2018
- Living with Dementia Event- 26th April 2018

We are planning to prioritise the Holderness area within the East Riding, by providing a series of roadshow events within October 2017 to March 2018 to key communities in Holderness including; Hedon, Withernsea and Hornsea.

In partnership with East Riding Carers Service, the Holderness roadshows will assist the promotion of Community Services and the Hull and East Riding Carers' Services' to:

- Identify hidden Carers
- Advise of Carers support & information available across our partnership
- Promote carers assessments
- Support access to financial advice and benefits
- Support access when dealing with legal financial affairs
- Support with legal documentation such as power of attorney and developing wills
- Support organising respite via care services and application for short breaks
- Provide information on carer's concessions
- Signpost to community activities/events



CHCP and East Riding Carers Support Service will be meeting bi-monthly to share best practice and information in regarding how to best support carers in the East Riding and how to better understand the specific needs of carers within Holderness.

CHCP and East Riding Carers Support Service are conducting internal staff surveys throughout October/November to gain understanding of the needs of employed carers and their specific needs.

We will work in close partnership with Carers' support services across Hull and the East Riding to ensure people with caring responsibilities are not restricted to their residential postcode when accessing service for themselves or the people they care for.

8.5 Commissioner focus: NHS East Riding of Yorkshire CCG

8.5.1 Section introduction by Public Health

The findings from section 8.5.2 have been derived from an in-depth discussion held in 2017, between Public Health and the Patient Champion (Lay Member for Patient and Public Involvement) of NHS East Riding of Yorkshire CCG.

Section 8.5.3 includes a list of key points that NHS East Riding of Yorkshire CCG felt should be considered for the Carers Strategy and needs assessment.

8.5.2 Key points about carers from an interview held in 2017, between Public Health and the NHS East Riding of Yorkshire CCG Patient Champion

1. Inclusivity in the local community

Carers (and the people they care for) are often excluded from society and the local community, when they actually want to be very much part of it. Even care homes are often not seen as part of community but simply a resource for the elderly or those in need of care.

2. Information to be given to the carer and for a wider range of conditions

Most information regarding the health of the cared for person (for example a leaflet given after leaving health care) is directed at the patient, with nothing specifically provided for the carer. Information can be provided for short term illnesses and also for progressive diseases such as cancer. Some conditions, such as cancer, have a plentiful supply of information written about them for use by the patient, but other conditions are often not so widely supported. The carer and patient will also interpret information differently, so literature should be written in a way so that it is understood by both of them. For example for the patient, instructions may state "this medication will work this way to make you better", but for the carer knowledge of what side-effects to look out for would be more helpful. Information about what the carer is expected to do and what they should/should not worry about would also be useful. The provision of a programme of education for carers, which does exist elsewhere in England, is recommended.



3. Transport and location

Not everyone can reside in a care home within the community that they call their home. This can cause problems to friends and family wishing to visit who don't have their own personal transport and have to rely on public transport.

4. Different needs for different Carers

Health and social care services should recognise that carers will have different needs. For example, carers looking after persons with dementia will face different challenges to those who care for children with learning difficulties. Some carers will care for both elderly parents and younger children. When health and social care provide a service or plan to put a new one in place, there is a need for flexibility and to show that there is diversity in the community has been considered. The tipping point for the requirement of residential care for persons with dementia (as one example), is when care is needed 24 hours a day, 7 days a week. If the carer could sleep then they could have that person at home longer, but this is not always possible.

5. Carers: Identification and self-identification

People don't call themselves carers, so how do health and social care services identify them or encourage them to identify themselves as a carer? Some carers don't recognise that they do actually provide a form of care. For example, there can be circumstances where a person usually manages to take care of themselves, but on occasion they can't and it is at this time they are supported by someone who has kept an eye out for them.

6. Carers seen in own right and their needs, their needs are a health remit

NHS ERY CCG recognise carers are part of the whole caring experience and need looking after in own right. It is generally felt that nobody listens to carers and nobody acknowledges the carers own lives, when they should be validated as an individual as well as a carer. Carers might be expected to give up work or feel they are forced to do so when care becomes more intensive. People can be very good carers but they have to worry about their own job at the same time which leads to very stressful situations. Therefore the needs of the carer should also be taken into account. The impact of caring on both mental and physical health should be considered, with issues relating to obesity, smoking and drinking needing to be addressed.

Employers need to be aware about how they can support people who are carers. They should consider that time may need to be taken for appointments, or that time out needs to be taken in the day to spend with the cared for person. Employers should also consider how they support staff experiencing end of life within their family.

Not everybody is a natural carer but there is an expectation that the family member picks up the caring role. There is a need to get the individuals to express what they really want themselves and also for the carer to say "I don't want to do it" without feeling shame.



7. Encourage carers to be part of care team:

Carers want to know what they can do to help the cared for person and be shown how to do it. Carers should be trained to perform some of the activities which enable support and allow them to feel they are contributing something valuable. Carers need specific knowledge about the condition of the person they are caring for, for example learning speech and language skills when caring for someone with communication difficulties.

Carers want to know how to converse better with the people they care for (especially for persons with dementia) and could have skills explained to them about how they can contribute when they make a visit at a care home, rather than just sitting there unsure in how to assist.

It is important for carers to be seen as integral part of that care team (for example: feeding, helping, supporting) alongside the professionals and for them to be listened to. Knowledge of allergies will be known by the carer and should not be ignored by the professionals.

8. Respite care

The availability of respite care (and the knowledge of how to get it) is essential, even if it is an extra pair of eyes to watch over the cared for person when out shopping for example. However, respite may mean at times splitting up the carer and the person they care for, which is not always easy for the carer unless they know the service is adequate. If the carer is unsure then they will spend all the time worrying and will not really get any respite at all.

9. Intimate Care

People who require intimate care might not wish this to be done by another family member and a stranger would be better. If not, this could change the relationship (which is a major source of support) between the cared for person and the family member.

10. Continuity of care

Having the same person as a carer is very important for persons with dementia. They may not recognise person but they are aware that they know the person and are calmer as a result. A change in the person providing care (or additional care alongside a family carer) may not be accepted by the cared for person. In this instance they may challenge the situation and often the only way to challenge it is to be physical. This risks the cared for person becoming renowned as a 'problem patient' and may result in a situation where there is a requirement for two carers to attend to the person, as it's not deemed to be safe.

11. Young carers

Young Carers in particular may not see themselves as carers, but young carers take pride in this role, especially when caring for a family member. They want to be part of the caring role to make it better for mother/father/family member and they should be enabled to do this. Intergenerational caring (between older people and younger people) works very well. There should be encouragement for youngsters to go into caring as a profession.



12. Policy changes and economic considerations

There have been instances where persons with caring needs get reassessed and then suddenly finding themselves losing money, as a result of a change of criteria. What knock on effect does this have for the carer? What happens if the carer suddenly becomes ill and cannot perform the caring role, are care packages in place to look after the person who needs care? Also, a lot of care services aren't arriving at the right time for the cared for person, this creates difficulties in enabling carers to keep their family member at home. There should be awareness (at STP level) of the impact of policy changes and service provision relating to carers.

13. The future

In commissioning it needs to be made sure that carers get an explicit mention in any specifications. Whilst not everyone presently has internet access, internet support will be more likely to feature strongly in the future and should be something to future proof. However the benefit of face to face, hand to hand, and personal physical contact should not be lost.

8.5.3 NHS East Riding of Yorkshire CCG: key points that should be considered for the Carers Strategy and needs assessment

- Identifying carers who might themselves have care needs that are not being met.
- Assessing and recognising carers' support needs using the Local Authority Carers Assessment and signposting them to the appropriate services to meet their needs, helping them to stay mentally and physically well and avoid being forced into financial hardship by their caring role.
- Involving carers in service development.
- Ensuring carers are equal partners in care planning with the service user if requested.
- Treat carers as valued individuals, with respect for their dignity, privacy and confidentiality.
- Ensure that carers are aware of their rights under the NHS constitution, the Health and Social Care Act, 2012 and the Care Act 2014.
- Support carers in a way that allows them to remain independent and enjoy the best quality of life possible. Such support should be tailored to meet individual needs and increase confidence and skills in self-management and prevention so that carers can care effectively and safely, looking after their own health and wellbeing and have a life alongside caring responsibilities.
- Support carers to make informed choices.
- Ensure Carers are universally recognised and valued as being fundamental to strong families and stable communities.
- Ensuring carers have access to information about their condition/s and relevant services.



- Building consistent relationships between carers and providers over time allowing them to turn to known individuals to co-ordinate their care.
- National indicator – health related quality of life for carers: data source GP patient survey, next release October 2016.

Additional comments from colleagues

- Under the category *Supporting carers to stay healthy* add: Improve access to psychological therapies to treat anxiety and depression and increase resilience.
- Within the main body of the document, where appropriate, include: ensuring carers are equal partners in care planning with the service user, if requested or if it is in the best interests of a service user who lacks capacity; and linked to it: ensuring service users are asked if they would like their carers involved in care planning.

8.6 Healthwatch

Results from the '2017 Healthwatch Carers Survey' can be found in section 5.3 of the appendix file.

9. Recommendations for action

An East Riding of Yorkshire Carers Strategy and action plan should be developed, based on the findings of the East Riding unpaid carers needs assessment.

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