



ONE HALTON CARERS STRATEGY 2020 - 2023 And DELIVERY PLAN

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Foreword

This new All-Age Carers Strategy in Halton aims to take a more joined-up and holistic approach to supporting Carers. Carers are a valued part of the community of Halton and Halton Borough Council (HBC), NHS Halton Clinical Commissioning Group (CCG) and the voluntary sector share a commitment to work together to improve the lives and opportunities for children, young people and adults who are carers in Halton.

Every year, across the country, more and more people take on a caring role. The enormous contribution of our carers not only makes an invaluable difference to the people they support, but it is an integral part of our health and social care system.

The Strategy and the Delivery Plan set out our current position, the areas for improvement that we need to focus on over the next 3 years and the outcomes for individuals that we want to achieve. The Delivery Plan has been developed in conjunction with children and adult carers, along with the key providers of services within Halton. We would like to thank everyone who has been involved with the development of this Strategy and Delivery Plan.

Rob Polhill
***Leader of the Council and
Chair of the Health and Wellbeing Board***

1.0 INTRODUCTION

1.1 The aim of this strategy

This high level strategy is designed to support all carers in Halton, and ensures that services across the borough work in collaboration with key partners to implement Halton's priorities, as well as national priorities. The strategy aims to identify areas that require improvement, based on the views of adults and child carers in Halton, that link in to the national statutory guidance and national consultation.

1.2 Who is A Carer?

A carer is someone who provides unpaid support to a family member or friend who, due to illness, disability, a mental health problem or an addiction, cannot cope without their support. Each carer's experience is unique to their own circumstances. Carers can be any age, from children to older people, and from every community and culture. Some carers may be disabled or have care needs themselves.

The Care Act's definition of an adult carer is ".....someone who helps another person, usually a relative or friend, in their day-to-day life. This is not the same as someone who provides care professionally, or through a voluntary organisation."

The Carers Trust¹ definition of a Young Carer is "...someone under 18 who helps look after someone in their family, or a friend, who is ill, disabled or misuses drugs or alcohol."

1.3 National Context

There are two main pieces of legislation that define how local authorities and providers support carers, namely the Care Act 2014² and the 2014 Children and Families Act³. The **Children and Families Act (2014)** aims to ensure that all **children**, young people and their **families** are able to access the right support and provision to meet their needs. The **Act** outlines a new Code of Practice for **children** and young people with special educational needs and disabilities (SEND).

The [Care Act 2014](#) and the [Children and Families Act 2014](#) introduced a number of reforms to the way that care and support for adults with care needs are met. It requires local authorities to adopt a whole system, whole council, whole-family approach, coordinating services and support around the person and their family and considering the impact of the care needs of an adult on their family, including children. This means that children's and adults' services must have arrangements in place to

¹ <https://carers.org/about-us/about-young-carers>

² <https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets#factsheet-8-the-law-for-carers>

³ <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>

assess young carers and ensure that no young person's life is unnecessarily restricted because they are providing significant care to an adult.

Carers are now recognised in law in the same way as those they care for. The Care Act gives carers the right to an assessment based on the appearance of need. Eligibility criteria do not apply to a carer's assessment (though they do apply for eligibility for services). The Care Act places a duty on local authorities to:

- Prevent, reduce and delay the need for support, including the needs of carers;
- Provide information and advice to carers in relation to their caring role and their own needs; and
- Work together with NHS partners and others in delivering the Care Act functions.

The NHS Long-Term Plan⁴ January 2019 states that carers will benefit from greater recognition and support. The NHS will improve how they identify unpaid carers, and strengthen support for them to address their individual health needs by introducing best-practice Quality Markers for primary care that highlight best practice in carer identification and support. In terms of Young Carers, the NHS will roll out "top tips" for general practice which have been developed by Young Carers, which include access to preventative health and social prescribing, and timely referral to local support services.

1.4 Local Context

Halton has a number of key local strategies and policy documents that are key drivers in areas of priority for health and social care. The documents are all accessible on the HBC website at www.halton.gov.uk, and include the One Halton Health and Wellbeing Strategy 2017 – 2022; Halton Joint Strategic Needs Assessment (JSNA) 2017; Pan Cheshire Local Safeguarding Children's Board Procedures 2017; Adult Social Care Local Account 2017/18; Safeguarding Adults in Halton: Interagency Policy, Procedures and Good Practice Guidance 2015 – 2018; and Children, Young People and Families Plan 2018 – 2021.

Overview of Halton's population

The population of Halton, as of 2018, is older on average than that of England.[1] There is a greater proportion of the over-all Halton population aged 50-69 than England and, a much lower proportion of the population aged between 15 and 44. This emphasises the potential for an ageing population to impact upon the borough's working age population. Although there are currently a lot of people of working age in Halton, many are within 10-20 years of retirement age and so this may present issues with workforce population in the future.

⁴ <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf>

The age breakdown of Halton’s population is expected to change over the next two decades. The proportion of people over the age of 74 is expected to swell and the proportion of children and people of working age is expected to contract. This is the case nationally also, but is predicted to be emphasised more so locally. As of 2018 12.2% of Halton’s population are aged 70 and above, whereas, in 2041 Halton’s projected population aged over 70 will represent almost a fifth (19.5%) of the entire population of the area.

1.4.1 What do we know about Carers in Halton

The last Census in 2011 identified that the population of Halton included 12% of carers, or 15,018, broken down as follows:

Indicator	Halton 2011 Census %	Halton 2011 Census number
Provides 1 – 19 hours unpaid care a week	6.4%	8,009
Provides 20-49 hours unpaid care a week	1.9%	2,440
Provides 50 or more hours unpaid care a week	3.6%	4,569

In comparison, from our own figures, we know that in Halton there are currently 5,534 carers who are known to our services. The majority of these are registered with the Carers Centre and receive support from them. This shows that there are many more carers out there who have not identified themselves as a carer, or have not registered with the Carers Centre.

The Carers Centre collate information on a regular basis and the information below is a snap-shot of their data, based on a few different categories, to give an overview of what we know about Halton’s carers. Below is a breakdown of all carers in Halton (that we are aware of) covering gender, ethnicity and age of carers in Halton as of August 2019. The data shows us that although the majority of carers in Halton are from a White British background, there are at least 12 other ethnicities of carers and this is something we need to consider when working with carers.

Gender	
Male Carers	1,842
Female Carers	3,692
Total	5,534

Age	
0 – 17 years old	719
18 – 64 years old	3,258
65 plus	1,557
Total	5,534

Ethnicity			
White British	5230	Indian	5
White Irish	30	Pakistani	1
Any other white background	18	Bangladeshi	7
White and Black Caribbean	5	Chinese	1
White and Black African	1	Black African	1
White Asian	14	Black Caribbean	3
Any other missed/multiple ethnic background	17	Non Stated	201
Total			5,534

Carers do have the opportunity to register formally as a carer through their GP so that their GP can signpost them to further support, but many carers do not know about this, and/or are not asked about their caring role by their GP. Although GPs record information about carers, the numbers are quite low in comparison to the data from the Carers Centre. This is an area that we need to focus on improving and will be highlighted in the Delivery Plan as an area for further development.

1.5 Where are the gaps?

- Understanding the full picture of carers in Halton.
- Standardised procedures for identification of carers through GPs.
- Ethnicity – increase the range of offers available to ethnic groups identified as carers – the Carers Centre can produce literature in different languages and forms (braille), if requested. They do not have a stock of these but can be ordered if needed. They have access to interpreters if there are any language barriers.

2.0 Identification and Recognition of Carers

The easiest ways to be formally recognised as a Carer are through your social worker undertaking a carer's assessment, registering as a carer through your GP or registering as a Carer with the Carers Centre.

2.1 How do I know I'm a Carer?

Many people with caring responsibilities don't see themselves as carers, but rather as a parent, spouse, son, daughter, partner, friend or neighbour. They support their family and do not think of themselves as "carers" or are not recognised as Carers by professionals and/or the community. Many carers would never use the term carer, even if they are one, as it's not how they wish to view their role and also it positions the cared-for person in the role of a dependent person, which they might not want to be viewed as.

Myth buster - If I reach out for support or register as a carer, the person I care for could get taken away by social services/or I could get taken into care?

This is the biggest concern we hear from carers wanting to reach out for support. **But the truth is**, this only happens in really extreme cases as a last resort, like if someone is being harmed or is in an unsafe situation.

2.2 What are the benefits to registering as a carer?

Research has shown that having support in your caring role can reduce feelings of isolation, help you to do more of the things that you like doing, improve health problems and help carers continue in their caring role.

By identifying as a carer (you don't have to be called that), carers can access lots of support to help them in their day-to-day lives, from social care services, the Carers Centre, the NHS or the voluntary sector or from more mainstream services like adult education centres, libraries and community centres.

When a carer registers with the Carers Centre they can access all their services which includes:

- Information and advice; emotional support; counselling; pamper sessions; podiatry; trips; training; coffee/support groups and carer funding.

The Carers Centre also refer onto other organisations for carers' assessments, respite, benefits advice, health improvement, etc.

Hannah's story

Hannah is elderly and has numerous health conditions. She lives independently in her own home however she also receives support from her daughter on a daily basis.

Hannah's daughter, Sarah visits her mum each day and enjoys spending time with her. They often have a cup of tea and a slice of cake and catch up on what each other has been doing throughout the week. Sarah supports her Mum to do her shopping, supports her with all of her medical appointments and assists with the practical aspects of her finances; going to the bank etc. Sarah does not consider herself to be a carer for her mum. She states that she provides the support as her daughter and does not wish to/feel it's important to be formally recognised as a carer.

2.3 Where are the Gaps?

- Improved joint working across partners
- Working in Schools to promote awareness of carers
- Information sharing and raising awareness of carers within GP Surgeries
- Publicity around carers to be more widespread- including the following areas:
 - Bus Stops
 - Social Media
 - Local Radio
 - Taxi's
 - Community Transport

3.0 Involving and Listening to Carers

A number of different events have taken place across the year to capture the views of carers to feed into this strategy.

3.1 Carers Consultation Event

On 7th March 2019 the Carer's Centre and Halton Borough Council organised a Carer's Consultation Event which took place at the Stadium in Widnes. All carers known to the Council and the Carer's Centre were invited and over 80 people attended the event.



3.2 Carers Week 8th – 16th June 2019

As part of Carers Week, the Carers Centre held a number of events to highlight the importance of the caring role and to connect carers to other carers in Halton. Over 230 carers attended the week's events which included two information and advice events, a bingo night and a cream tea afternoon.

Carers also had the opportunity to complete a short questionnaire to feed into the development of this strategy based on what carers thought was working well and what could be improved. This also included a session with young carers through the R-Time Young Carers Group.

During carers week the Carers Centre held outreach in several venues throughout the borough promoting carers and identifying members of the public who had a caring role. Within their office they hired a marquee for the garden which enabled them to hold events during the week. These events included an adult carers information day where we invited 20+ services from the borough to come along and host a stand on the services they offer in the borough, the day was then for carers to drop in at any time to find out what support is available.

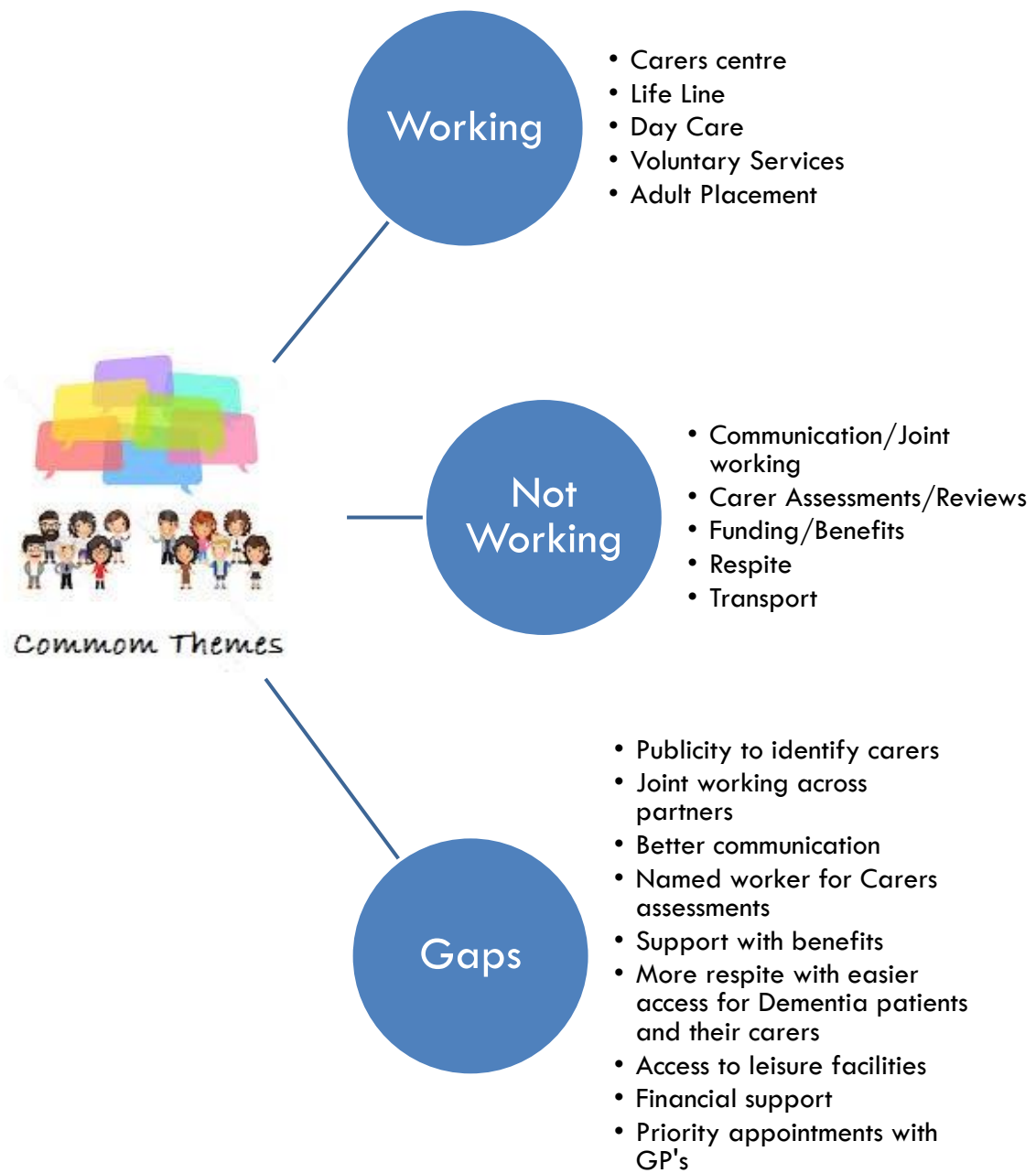
The Carers Centre also had a similar day dedicated to young carers support and services in Halton. They were able to hold three fundraising activities during the week which included a prize bingo, a cash bingo and a craft fayre. All these events were open to registered carers and residents of Halton. The final event was held on Friday which was a strawberry tea event where carers were invited to the Carers Centre to celebrate the work they do, a spot of lunch was provided with entertainment.

For Halton Carers Centre, Carers Week was a great success and feedback that was received from Carers and other organisations in the borough was very positive.

3.3 Carers Forum – 15th October 2019

This was a drop in event held at the Stadium in Widnes. Carers were offered the opportunity to have their voice heard, and to review the draft carers strategy. For those people who were unable to attend the event, the Carers Centre sent out the strategy on email and a questionnaire was distributed.

Common themes have been pulled out from all the feedback we have received and are captured below. More detail can be found at the Appendix to this strategy.



4.0 Young Carers

4.1 Education

Of all the different services and agencies, schools come into contact with the biggest number of young carers in most communities though not all will be aware just who their young carers are. Every school in Halton has a designated person for young carer issues. Young Carer Workers from the carers Centre liaise closely with schools and school can often provide a safe space for young carer drop in services and reviews to take place.



Myth buster - Will people treat me differently if they find out I am a young carer?

We know that young carers can worry that they will be bullied if people find out. However, we also know that people who bully others often do so because they feel the person they are bullying is "strange" or "different." There are many thousands of young carers in this country; there is nothing strange about it. The more young carers who come forward and are open about who they are, the less likely they are to be bullied. If you do find that you are bullied, there are lots of things we can do to help.

4.1.1 Young Carer in Schools (YCiS) Award

Halton schools are encouraged to apply for the YCiS award. This national initiative was developed jointly by the Carers Trust and The Children's Society and is free to all schools, making it as easy as possible to support young carers and recognise good practice. The award process comes with a range of resources, guidance, and practical tools to help your school raise awareness about issues affecting young carers and remove any barriers to education and school life.

Bronze, silver and gold awards are all based on five key principles of understand; inform; identify; listen and support.

Schools in Halton have found these principles build on their existing initiatives to support vulnerable pupils in the school community. Halton Carers Centre and representatives from the young carers strategy group can be contacted to support schools with the application process.

4.1.2 Educational opportunities

The 14 – 19 Team in Halton work with young people who are not in education, training and through their work have the opportunity to identify if there is a barrier to participation because of caring responsibilities.

Those that are in further education, training or employment are the ones we are less likely to have recorded as a Young Carer, especially if they've transitioned from school straight into Post 16 education or training without needing support from the 14-19 team. This means that the overall figure for Post 16 Young Carers that is held on this system is not a true reflection of all 16 & 17 young carers in the borough.

4.2 Where are the Gaps?

- More choices for young carers
- More Youth clubs
- Courses: e.g. First Aid refresher course
- Support for young carers who are siblings of disabled children

Jack's story

Jack withdrew from Further Education course due to the pressure of his caring responsibilities and the effect this was having on his own physical health. A Young People Caseworker from the 14-19 Team referred Jack to an Engagement Worker from Career Connect to explore Jack's short and long term careers aims. Further to this Jack was referred to a Coach, commissioned by the 14-19 Team, who provided support to address emotional/environmental and health barriers to participation in education or training. With intensive support Jack obtained part time employment and plans to build on this by gaining an apprenticeship in the near future.

Holly's story

Holly didn't achieve full potential in school due to the complexities of her caring responsibilities. At 16 years old Holly did not progress to Post 16 education or training. A Young People Caseworker from the 14-19 Team referred Holly to a Coach, commissioned by the 14-19 Team, who provided intensive 1-1 and peer coaching sessions. Holly progressed to completing an employability programme, including attaining Level 2 Maths and English and plans to build on this by gaining an apprenticeship in the near future.

Young Carers Poem

I am a Young Carer!

*We are young carers part of an elite group,
Part of a special task force, the unseen troops.*

*The camouflage we wear, truly is the best.
We walk through the streets, yet look just like the rest.*

*We work around the clock, to help the ones we love,
And we will never stop, until the work is done.*

*Our mission is a tough one, often misunderstood,
Not able to do the kinds of things, a child of our age should.*

Halton Young Carer – aged 12 years

5.0 Transition to Adulthood

As young carers reach the transition age (between 16 and 25 years old) they will face the possibility of leaving school to attend college, university, training and find a job. These are significant challenges for any young person and can be considerably more challenging for young carers.

Young adult carers (between 18 – 25 years old) can have very different needs and circumstances to young carers and services need to reflect this difference.

Young adult carers will also make the transition from services provided by Children's Services to those provided by Adult Social Care, as well as engaging in the universal services aimed at supporting adults.

When a young carer reaches the age of 16, the Carers Centre will include them in both young carer and adult carer information and activities to support them during the transition to adulthood. This can be a difficult time for some young carers, especially if there is only one carer in the family.

Young people in Halton have told us that they struggle in the transition period as they feel too old for traditional children's services but that equally adult services do not seem to always appreciate their needs as young people. This is an area for improvement in Halton.

For young carers transitioning to adult carers the Carers Centre follow the Young Carer – Adult Young Carer plan. When a young carer turns 16 years of age they are introduced to the adult carers support team and given a named support worker so they can, over the two years, start getting to know the adult team. They can also use both Young Carers Services and Adult Services too in this timeframe.

5.1 Where are the Gaps?

- Support with Transport costs, e.g. there are bus passes available to travel to and from school, but out of school it is difficult to access activities.

6.0 Employment and Skills

Enabling people with caring responsibilities to fulfil their employment and skills potential

The Department of Health and Social Care "Carers Action Plan 2018 – 2020"⁵ states that around one in nine working people have informal caring responsibilities, but many of these experience substantial challenges in balancing employment and their caring role.

A government-funded and independently evaluated project looked at what works to support carers to remain in or return to the workplace. The Carers in Employment⁶ (CiE) project took place between 2015 and 2017 with nine Local Authorities who were encouraged to develop local solutions to support carers to remain in or return to work. The project found that there is a complex set of challenges when supporting carers in work, and highlighted the importance of raising the profile of working carers as a group in the workplace. Some employers involved with the project introduced carer-friendly HR policies and practices and encouraged flexible working arrangements.

Denise's story

Denise cares for her husband; he had had multiple mobility and health conditions for several years. She was feeling overwhelmed and contacted the project team; she received funding for a weekend of respite care. Staff encouraged her to approach her employer's HR department and found her employers to be supportive and flexible. In addition to flexible working, her employer teamed up with a third party specialist care agency to provide emergency support. Denise is now entitled to five hours paid care from an outside agency, funded by her employer.

Part of the work of Halton's Carers Centre involves going into workplaces to work with employers to identify and assist working carers. This entails providing tips and practical examples to employers of ways that can help them make the most of their working carers workforce, improve their staff wellbeing and reduce both turnover and sickness. They also provide regular drop in sessions with several organisations within Halton for working carers which are based at the worksite so that carers who cannot attend the Carers Centre during the open hours can meet with Centre staff to discuss their caring role.

⁵

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/713781/carers-action-plan-2018-2020.pdf

⁶ <https://www.scie.org.uk/carers/employment>

6.1 Where are the gaps?

- Employer support for Working Carers in organisations within Halton.

Myth buster - Is it true that if I register as a carer I won't be able to stay employed or continue studying?

Caring can of course be hard and time-consuming, so often people find it hard to continue working or studying. But the truth is, registering as a carer means you can get access to the support you need to enable you to continue working, studying and caring, if that is something you wish to continue. Carers often tell us they want to stay in employment or continue their academic or career paths, and the support and advice we offer can help you achieve this.

7.0 Older Carers

“Responding to the Voice of Older Carers – building on what works”⁷, Research in Practice states that the number of older carers is increasing and for many people becoming a carer later in life involves the transition from a more independent life to the role of a carer, when social care professionals may become involved in their lives, often for the first time.

The Princess Royal Trust for Carers (2011) carried out an online survey of 639 older carers and highlighted these key findings (which although it is nearly 10 years old, are still pertinent today):

- Carers aged 60-64 experience the most financial difficulty, often juggling work with caring responsibilities for more than one person.
- The majority of older carers report caring for 60 or more hours per week – particularly those carers aged 70 or over.
- Two thirds of older carers have long-term health problems or a disability themselves. Commonly reported conditions are arthritis and joint problems, back problems, heart disease, cancer and depression.
- One third of older carers reported having cancelled treatment or an operation they needed due to their caring responsibilities.
- Over three-quarters of carers aged 60-69 said caring had a negative impact on their mental health.
- Less than half of carers aged 70 and over who have to lift the person they care for do not feel they can do this safely and confidently.
- More than eight out of ten older carers have worries for the future, about what will happen to the person they care for if they can no longer care.
- More than one third do not get breaks away from caring, and a further third get a break only once every two to three months or less.



7.1 Age UK Mid-Mersey

In 2011 there were 8.2 million carers in the UK, but by 2015 these numbers had risen to over nine million; these carers are helping loved ones who have increasingly complex and multiple care needs.

Of these, there are now over two million carers aged 65 and over, 417,000 of whom are aged 80 and over and many of them have themselves health and social care needs. Age UK analysis shows over 37 per cent of carers aged 80 and over are providing 20 hours or more of care a

⁷ www.ripfa.org.uk

week, while 34 per cent are providing 35 hours or more. Yet nearly two thirds of older carers themselves have a health condition or disability, while 72 per cent report feeling pain or discomfort, rising to 76 per cent for those who provide 20 or more hours of care a week. Carers often also feel lonely and isolated or excluded from society.

Further evidence from Age UK research indicates that although overall the numbers of carers are rising, there has not been a substantial increase in the proportion of the population providing care. This is set alongside rapidly rising levels of unmet need and the impact of changing family structures, greater geographic dispersal, and rising State Pension age this suggests that the provision of informal care has not been able to fill the gap left by declining provision of formal care services.

Locally, Age UK Mid Mersey have been a strong advocate for the ethical care charter and worked in the community to highlight the work done by carers, both paid and unpaid in supporting the often desperate care needs of an ageing population. Much of our core work, funded by the local authority includes the provision of extensive and often complex face to face advice and support to older carers and families to access a range of support to improve the welfare, living conditions, independence and quality of life of local older residents. The demand for this work is constantly rising and increasingly complex.

Our Community work on dementia and on safeguarding dovetails into care needs and the organisation is active on a range of strategic boards that influence the shape and quality of services in the care sector. A live case study below demonstrates the impact on and support given to an older carer in Halton.

Age UK Mid-Mersey - Halton Case Study

ABOUT THE PERSON
A married couple Tom and Sadie are aged 70 and 68 respectively. They live in social housing in the Widnes area. They are both retired and have both been in ill health for several years. Also living in the family home is a dependent adult son, whom Tom and Sadie care for with limited input from outside agencies.
WHAT WAS THEIR PROBLEM?
Tom had seen the Age UK Mid Mersey (AUKMM) Widnes Market outreach stall whilst he was out shopping. He approached the AUKMM stall with concerns initially about his adult son who was in ill health but was not claiming any benefits. AUKMM Information Officer was able to explain to Tom that because his son was under 50 years of age AUKMM would be unable to help directly with his son however it was

explained to Tom that we could do a warm referral to Halton CAB to obtain help and support for his son.

The Age UK Mid Mersey Information Officer then asked Tom about his circumstances and if there was anything we could help with further. Tom then revealed that he was in rent arrears with his landlord and struggling to manage due to his own poor health. Tom revealed that his wife was in very ill health and had her Personal Independence Payment (PIP) benefit stopped because she did not attend for a medical. Sadie had been on Disability Living Allowance (DLA) for 10 years due to her health and finds it extremely difficult to look at all her health problems and could not face the stress of going to have a medical assessment. The loss of income has exacerbated the family's financial situation and wellbeing.

WHAT DID YOU DO TO MAKE A POSITIVE DIFFERENCE?

The information officer suggested another ill health benefit called Attendance Allowance and ordered the form and explained to Tom that Sadie would not have to attend a medical to qualify for the benefit. The Information Officer also explained that they would do a full benefit check to get them both the help they needed.

WHAT OUTCOMES DID YOU ACHIEVE?

The Age UK Mid Mersey Information Officer arrange an appointment to go out to see Tom and Sadie on a home visit to complete a full benefit check and the attendance allowance forms for both of them subject to qualification.

The home visit produced a successful outcome with both Tom and Sadie awarded Attendance Allowance at the higher rate of £85.60 per week in addition Sadie received a backdated payment of £1112.80.

The Age UK Mid Mersey Information Officer also contacted Widnes Link and the couple received a backdated rent award of £1276.34 to cover all the rent arrears.

ADDED BENEFITS

Tom and Sadie were not on guaranteed pension credit and once Attendance Allowance was awarded the Information Officer was able to secure a payment of £34.95 per week this included the care element so both clients are now able to receive free dental care and spectacles.

In addition, to help with winter fuel bills the Information Officer secured Warm Home Discount of £140. Their son who was referred to Halton CAB is now on

Universal Credit and in the process of applying for PIP and this has taken away the financial pressure the family was experiencing.

QUOTES/FEEDBACK FROM OLDER PERSON

What did the older person say about the service, its quality, the difference it's made?

Sadie in her own words said "relief I do not have to go through all the stress of a medical a lot of pressure has been taken away. I feel thankful my husband approached you and you took the time to visit me and I feel grateful for all the help you gave me and how sympathetic and professional you have been".

Tom visited Widnes Market recently and advised the Information Officer that the family is taking a three day holiday in Wales to visit a relative something which would have not been possible before the intervention.

7.2 Where are the gaps?

- More support with Direct Payments
- Availability and range of Respite Care especially in terms of pre-booking
- Training for older carers.

8.0 Carers of People with Dementia

Caring for someone with dementia can be different from caring for people affected by other types of illness or disability because of the complex, unpredictable and progressive nature of the illness. Carers of people with dementia are likely to have higher than normal levels of stress, and report higher levels of depression than carers of other older people⁸. Consequently, carers' needs for practical and emotional/psychological support to relieve the emotional stress of caring are especially high.

The Carers Trust paper 'A road less rocky – supporting carers of people with dementia' (revised 2018) identified that carers experience common gaps at critical points in the dementia journey including from diagnosis, taking on an active caring role, dealing with a decline in a loved one's capacity, when decisions about when residential care need to be made and advanced care planning.

There are a number of evidence based resources to support the dementia carers' journey, including:

- NICE Guideline 97 'Dementia : Assessment, management and support for people living with dementia and their carers'
- NICE Quality Standard 184 'Dementia'
- Alzheimer's Society Local Dementia Profile for Halton recommendations
- Prime Minister's Challenge on Dementia 2020

In response, Halton has in place a number of different services for carers of people with Dementia:

- **START** – Psychological resilience building course for family carers of people with dementia, delivered by the Carers Centre
- **Dementia Carers Group** – support for carers of people with dementia run by the Carers Centre.
- **Post diagnosis course** – information provision for both the person with dementia and the carer about practicalities of living with dementia including end of life planning, financial and legal matters as well as links to local support, delivered by NHS North West Boroughs Trust
- **Dementia Advisor service** – 1:1 information, service navigation, signposting and practical advice delivered by The Alzheimer's Society.
- **Admiral Nurse Service** – community based service supporting the families/carers of people with dementia who have complex needs.
- **Voluntary and community sector support and activity groups** – there are a number of groups such as memory cafes, activity and social groups and friendship groups.
- **Resources** –Including 'dementia books on prescription' and Halton Dementia Action Alliance website

⁸ Moise, Schwarzingger and Um (2004) *Dementia care in 9 OECD countries: a comparative analysis*, OECD Health Working Paper no. 13, OECD: Paris

Halton Borough Council are reviewing local dementia priorities for adult social care as at September 2019. Priorities for Halton that are directly relevant to carers include: advanced care planning, growing Halton's dementia friendly community, supporting research and enabling carers to maintain their caring role – including access to respite services.

8.1 Where are the gaps?

- More Dementia-friendly activities to do in Halton
- More publicity around information on places to go for people with Dementia
- More services provided by the NHS for those with Dementia
- Raise awareness of accreditation for Dementia-friendly places in Halton.

My Personal experience – Caring for relatives**Christine Lee**

In 2007 my dad began to experience problems with his memory and ability to eat and swallow. After numerous phone calls, appointments and assessment he was diagnosed with vascular dementia. At the time, myself and family had no insight as to what this meant and how it was about to impact on my dad's life and all of us as a family.

The problems and concerns his illness presented were overwhelming. We all felt we were lost and didn't know where to turn for help. The support that was offered in the form of social groups for carers, activity group for dad, training sessions through the carers centre were inaccessible as our lives were completely directed by caring for my dad and supporting my mum. Between our own family commitments and work there was no free time to attend any groups and my dad would not entertain attending anything.

I began to do my own research on dementia and found useful information on the Alzheimer's society website about the illness itself, benefits and setting up an L.P.A which proved to be invaluable.

At no point did I or my family identify ourselves as being carers for dad, we were simply looking after him.

Further down the line a social worker became involved and mentioned a carer's allowance break fund that we could all apply for. This we did and it was helpful to be given some money to spend on ourselves, however what we really required was a regular break from the caring role that dictated our lives, providing an opportunity to take a break, rest and consider ourselves and our own needs and interests, in order to successfully continue in our caring role and endure the emotional and physical demand it placed upon us.

My dad lost his battle with dementia in 2014. His journey was long, painful and frustrating. As a family we did feel let down by the health and social care professionals.

I am now a carer for my mum who was also diagnosed with vascular dementia 4 years ago. My previous care experience gave me an insight as to what to expect. We do now receive 4 free hours carers break support each week that makes a difference. I feel that people living with dementia, their families or carers should receive more financial support in order for them to continue to live well with dementia at home and it should not be means tested. This I believe should be the case for anyone living with a terminal illness.

9.0 Health and Wellbeing of Carers

When it is your responsibility to look after someone else, it's very easy to forget to look after yourself too. It is more important than ever to make sure that as a carer, you are as fit and healthy as you can be to so that you are able to provide the best care and support for the person you care for. Around 71% of carers experience poor physical or mental health.ⁱ It is important that you make time for you, even down to making and keeping regular health check-up appointments with your GP and your dentist. There are some specific things you can do to help yourself:

9.1 The impact of being a Carer

The impact of being a carer can be both physical and emotional. Not all carers will recognise themselves as such as often see their role as just a natural part of their family life. Saul Becker is a leader in the study of young carers and has developed resources to help workers explore the impact of their caring role through tools and questionnaires that help measure the range of physical care tasks undertaken as well as the positive and negative aspects of caring. These tools are readily available to practitioners and carers alike. (Joseph, Becker & Becker 2012⁹).

Young Carers in Halton have spoken about the positive impact of being a young carer such as building stronger relationships with family, learning life skills and increasing their confidence. Being a young carer can be positive and rewarding. Families and practitioners can work together to ensure that the caring role is not excessive, harmful or inappropriate.

9.2 Mental health

Looking after someone else can be an emotional challenge as well as a physical one. Taking care of your own mental health and well-being as a carer can be difficult and carers are more likely to experience emotional stress, depressive symptoms and clinical depression. The carers UK annual Survey 2015 showed that of 5000 carers surveyed, 84% of carers feel more stressed; 78% feel more anxious and 55% reported that they suffered from depression as a result of their caring role.ⁱⁱ

It is important that carers can access a variety of care and support for their mental health. This may be as regular respite to engage in non-carer activities and hobbies or just to take time out. It may be ensuring access to mental health and support services such as talking therapies, IAPT, social prescribing, or peer support services are available. It is important to ensure that all services and programmes are flexible enough to enable carers to make good use of them. Primary care services must also

⁹ Stephen Joseph, Fiona Becker & Saul Becker; 2012; *Manual for Measures of Caring Activities and Outcomes For Children & Young People (2nd Edition)*; Carers Trust in association with Young Carers International Research and Evaluation, School of Sociology and Social Policy, The University of Nottingham. ISBN 13 9780853582533

ensure that they are aware of carers to be able to offer the most effective treatment and support options and engage in mental health discussions at any opportunity.

9.3 Flu Immunisation

Flu can be an unpleasant illness, but for older people or those with a long term health condition it can be particularly serious and lead to complication such as bronchitis and pneumonia and can often result in a hospital stay. The flu vaccination is offered free to carers and is available at the GP or local pharmacy every year from September to March. Call your GP to arrange the most appropriate time to have your flu vaccination, a local pharmacy may have a wider range of time availability that better suit around your caring commitments.

9.4 Cancer screening

Cervical cancer screening is a programme to check the health of the cervix (the opening of the womb from the vagina) and is available to women aged between 25 and 64. Appointments can be booked at your GP, if you haven't received a reminder for a while, call your GP and check if you are up to date. There are a variety of options available to carers to make it easier to attend; your GP may be able to make an appointment at a convenient time for you, but screening can also be done at GP extra which offer evening and weekend appointments or at Family Planning services, which may be more flexible around times that suit you best.

Breast cancer screening is a programme offered to women routinely between the ages of 50 to 70 every three years (though in some areas women may be called from 47 to 73 years of age). The screening checks for anything abnormal in the breast tissue. If you think you are overdue for your breast screen, call your GP or the Breast Screening Unit at Warrington Hospital (www.whsthbss.nhs.uk). In Halton, the Breast screening is provided in rounds, in a mobile unit within the community, but if you are overdue and the unit is not currently in Halton, you may need to go to the hospital for your screening. Call the breast screening unit and they will be able to help you find an appointment time that may fit best around your caring role.

Bowel cancer screening is a simple test that you can do in the comfort of your own home and posted back in an envelope, no need for appointments. The test is to look for blood which could indicate a problem in the bowel. The test is offered to everyone every 2 years from the age of 60 to 74. If you haven't completed your kit, you can call **0800 707 60 60** to request a new one.

9.5 General health check

If you are not feeling your best, you can make an appointment at any time to chat to your GP. The NHS also offer a free Health Check which is a check-up for adults aged 40-74. It is designed to spot the early signs and risk factors of health conditions such as stroke, kidney disease, heart disease, type 2 diabetes and dementia. As we get older

we are at increased risk of developing these conditions. The Health Check helps to find ways of lowering your risk. If you are in the age range and haven't had a recent Health Check, call your GP.

It is important to keep your home, and the home of the person you support, warm. Living in a cold home negatively affects health and wellbeing. The very young, the elderly and those with health conditions such as cardiovascular and respiratory disease are particularly vulnerable to the effects of the cold. Support is available in Halton to help those who are struggling to heat their home or afford the costs of heating. Our partners can provide advice on the best fuel tariff for you and any benefits or government discounts you may be eligible for. They can also access support for energy efficiency measures such as new boilers or for managing fuel debt, where applicable. You can access this support free of charge via the council website's self-referral form, or by contacting our partners Energy Projects Plus (0800 043 0151) or Cheshire Green Doctor (0808 168 3547) directly."

9.6 Where are the gaps?

- NHS Services not being fully up to date on situation
- Carer lists at GP Surgeries for priority appointments
- Podiatry appointments are over subscribed
- Young adults, people who have physical illnesses, not enough support
- Publicise access to leisure facilities – such as Halton Leisure Card

10.0 When the caring role ends

When the caring role ends, carers become known as “former” carers. This might happen for a number of different reasons, e.g. the cared for person goes into permanent residential and nursing care, the cared for person does not require care any longer or the cared for person passes away.

The carer may have been a carer for long time and may still require some support around the changes that have happened.

In Halton, the Carers Centre continues to support former carers with a range of services to help them re-adjust to their change in circumstance. This includes counselling around “end of caring” issues, practical support and advice in the event of the death of the care for person, and a training programme offering courses such as how to access leisure, training and employment opportunities, skills for “moving on and being independent” and volunteering opportunities.

When a caring role ends and the carer informs the Carers Centre of this either via notifying the centre or at review, if they wish to remain on the books for a further year they will complete a review of how they are. During this phase the Carers Centre will remind them about the counselling service as well as the former carers group and that they are entitled to continue accessing services, bar personalised breaks, for a period of up to 12 months.

Some quotes from former carers:

'I look forward to meeting my friends at the group each month, we arrange to go on days out and holidays during the year, we are there if anyone needs to talk about their problems.'

'I enjoy our once a month meeting groups and our days out, we have food and chat. It really is a lovely group to be part of.'

'I appreciate the support I get from the group, it is a friendly atmosphere where you can have tea & cakes and feel fully supported.'

10.1 Where are the gaps?

- Leaflet/checklist to publicise the following areas:
 - Benefit checks – follow-ups, how to refer to Bereavement Services, voluntary work/paid employment, support when registering a death, automated support when caring role ends, e.g. letter to benefits agency, carer’s centre, bereavement support, etc.
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FEEDBACK FROM CARERS

APPENDIX

What are we trying to achieve?	What is currently working?	What isn't working?	Where are the Gaps?
Identifying / recognising carers	Having Support Family Reablement GP Carers Association Information from individual support groups	Communication No flexibility for working carers with GP Lack of services in certain Demographics Barriers created due to data protections and confidentiality Integrated support, networking, not enough support or awareness Knowledge of accessibility Employees not recognizing carer responsibilities Council Carers	Joint working across partners Working Carers Working in Schools GP Surgeries Information Card Publicity in the following areas: Bus Stops, Social Media, Local Radio, Taxi's, Community Transport
Benefits of Registering as a Carer	The Carers Centre Information Advice Support Trips Activities Therapies Treatments Supportive and Proactive	Communication Information on access to services and benefits	Joint working across Partner agencies, ensuring that all carers are aware of the carers centre and the support they offer
Involving / Listening to Carers	Being kept informed Feeling looked after Adult Social Services Carer Centre Collaborative Working	Not enough practical support from HBC Public Transport Access to GP appointments Feeling isolated Communication Access to information Interpersonal relationships with cared for person Respite difficult to access No support or inclusion for carer Integrated support, networking, not enough support or awareness Services are slow, getting no answers Benefits complex	Communication/joint working/linking in with partner agencies More effective communication between HBC and Carer Centre Named worker for Carers Regular contact with HBC Respite breaks in own homes Day Services Information to be available in Libraries

		Carers assessments	
Young Carers	CHAPS Chestnut Lodge Special School	Choices for young carers Appeals to be supported for siblings of disabled children, but lack of awareness of what's available for parents No child hoist facilities in HBC No understanding of what parents need Woodview LA – NHS Local Service for Disabilities	
Education	First Aid Course START Course		Courses: e.g. First Aid refresher course
Transition to Adults		Transport is expensive Changes to benefits should be automatic	Support with benefits
Employment / Skills			
Older Carers	Lifeline Stroke Nurses	Direct Payments / Respite	
Carers of People with Dementia	Easing the pressure since diagnosis Lifeline Admiral Nurses	Dementia friendly things to do Looking where to get the support from More information on places for people dementia More respite Support with Cost Direct Payments / Respite	Support with visual and hearing impairment More respite for longer More services provided by the NHS for those with dementia
Health and Well-being of Carers	Liaison with Carer Centre families understanding Mental Health	Feeling lonely	Access to leisure facilities
Mental Health	Adult Placement CPN Support	Discharge from Brooker Centre	Communication
Impact of Being a Carer	Plenty of activities on Getting a break Good support Support for cared for person	HHC Podiatry appointments are over subscribed Discharge from Brooker Centre Benefits Working / Caring balance	Young adults, people who have physical illnesses, what support is available? Not enough social care support

		<p>If the person being cared for doesn't recognise they need caring for. Then it is hard to get letter from professional to confirm your caring role</p> <p>Feeling that you have to manage on your own</p> <p>No support internationally (except blue badge)</p>	<p>Respite care for carers and help financially with respite care</p>
General Health	Support from GP	NHS Services not being fully up to date on situation	Carer lists at GP Surgeries for priority appointments
When Caring Ends	Carers Centre – support 12 months after	Bereavement services and support - ASC need to know about and how to do referrals	<p>Benefits checks – need to ensure follow-up</p> <p>Consider referral to voluntary services – needs to be right for the individual</p> <p>Better support on how to register death etc.</p> <p>Confusion over what point do we stop supporting a carer</p> <p>Include note on carefirst on death notification as to whether they had a carer – could trigger follow-up e.g. letter to benefits agencies, carer's centre, etc.</p> <p>Is there a role for the contact centre in relation to follow up</p>