



This strategy is dedicated to Jeanne Carlin who inspired many with her passion and commitment to the improvement of carer’s services in Hull.

Through her dedication, hard work and good humour, Jeanne was a strong and generous supporter of adult social care and contributed a great deal of her time and energy to ensuring the

necessary improvements were made to provide a better future for carers and those who they care for. Not only did Jeanne make an impact locally, her voice was heard nationally and she worked tirelessly to make sure that the vulnerable adults from our city were well represented.

She is, and will continue to be deeply missed.



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Councillor Gwen Lunn

1. Executive Summary

I am pleased to present Hull's Integrated Carers Strategy 2020 – 2025 which has been developed by the Hull Carers Partnership Board (HCPB). This strategy has been produced in response to the government's national carer's action plan 2018 – 2020 which built on the national carer's strategy published in 2008 setting out a 10 year strategy to support carers. The purpose of this strategy is to set out our priorities and strategic direction over the next 5 years. This document contains:

- Background information around the role and impact of caring including the national and local context
- What is currently available to carers within the city of Hull
- How the strategy was developed, the vision and the key priorities which have been identified by the HCPB for the next 5 years
- How the strategy will be implemented and monitored to ensure it is meeting the objectives including an action plan for the first year

In order to identify the priorities set out in the strategy the HCPB set up a major 'system wide' consultation process to engage with carers in Hull. The consultation process focused on gathering responses to 3 key questions, these were:

- What information, advice and support is currently available for specific groups of carers?
- What would specific groups of carers like the information, advice and support to be in the future?

- What specific needs do the groups of carers have?

These responses were collated and the following 4 priorities were identified with the aim of improving the overall wellbeing of carers in Hull:

- Priority 1 – Integrated information and advice
- Priority 2 – Jointly commissioned integrated prevention and early intervention
- Priority 3 – Shared integrated respite activity which supports specific situations
- Priority 4 – Share collaborative statutory activities

The HCPB is responsible for the development, delivery and monitoring of the local strategy. It consists of a range of representatives from partner organisations and stakeholders, working in collaboration to try to push this agenda forward and develop ways of improving services for carers and the people they care for. Our aim is to develop and maintain support arrangements for carers in Hull to enable them to live healthy, independent and meaningful lives. By improving professional's and the public's understanding of who a carer is, how to identify them and the provision of good quality information, advice and services focusing on prevention and early intervention. Carers will be enabled to feel empowered, recognised and valued for the role they undertake. Additional training is required for carers to support them to develop the skills and knowledge required to undertake the caring role as effectively as possible particularly taking into account the additional difficulties highlighted by the recent global



pandemic. We should never lose sight of the fact that people who act as ‘carers’ for their family or friends are individuals in their own right and should not be defined by merely their role of carer.

This strategy is particularly close to my heart due to my own personal situation as a carer for my son. The recent situation with regard to Covid-19 has even further highlighted the huge role that informal carers play in our society and the need to ensure they are fully equipped and supported to continue in these roles. There has been some amazing and inspiring work done in Hull during the pandemic which has shown the possibilities

available when we work in a creative and imaginative way. I am encouraged and excited by the opportunities presented by collaborative working within Hull and feel that by working together, utilising new ways of working and not just listening to but hearing the voices of the carers of Hull we can improve their lives and the lives of those they care for.

Councillor Gwen Lunn

Cabinet Member – Portfolio: Adult Services & Public Health
Hull City Council



2. Background and Information

Who is a carer?

The Carers Trust defines a carer as “anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.” Many carers do not see themselves as carers particularly when they are caring for a close family member such as a son, daughter, mother or father. Anyone can become a carer at any time in their life as a result of circumstances and it’s likely that every one of us will have caring responsibilities at some time in our lives.

This document will cover carers who fall into the following categories:

- Adult carers – an adult who provides or intends to provide care for another adult (an “adult needing care”)
- Young carers – a person under 18 who provides or intends to provide care for another person (of any age, except where that care is provided for payment, pursuant to a contract or as voluntary work)

Prior to 2014, support to carers was not legally recognised. The Care Act 2014 and the Children and Families Act 2014 recognised carers of all ages in their own right and introduced an entitlement to all carers regardless of the support that they provide to have an assessment to determine if they need help.

What do carers do?

Carers tasks vary widely and may include but not limited of any of the following:

- Personal care such as washing, dressing, getting in and out of bed or to the toilet
- Support to access activities, shopping, and community
- Support to manage finances, bills, property and household management tasks
- Emotional support

Many carers juggle their caring role alongside employment, education and/or family life which can be stressful and impact on the health and wellbeing of the carer.

Impact of the carer’s role

The physical, emotional and psychological demands of caring can be demanding and stressful. Caring takes a toll on carers’ education and employment opportunities, including career development, promotions and pay rises, as well as impacting on carers’ ability to work at all. Indeed many are forced to give up work altogether or take early retirement or reduced hours. The caring role can have a negative impact on the carers physical, emotional and mental health with carers twice as likely to suffer from ill health as non-carers. More than half of those who provide more substantial care have suffered physical ill health as a result of caring, and more than 70 per cent of those caring round the clock have suffered mental ill health at some time.

Carer's allowance

Carers who take on an unpaid caring role for 35 hours or more per week may be eligible to receive Carers allowance. This is a benefit currently of £67.25 a week. There is a cap of £128 per week on how much a carer is able to earn from work whilst still being eligible for the Carers Allowance. While this may be good for those in low paid employment this impacts on those on the National Living wage (NLW) as the recent increase means that anyone working 16 hours a week or more on NLW would receive £131.36 per week making them ineligible for carers allowance. If a carer reduces their hours down this can impact on their eligibility to receive working tax credits which would then impact on them financially resulting in them having to choose between receiving working tax credits or carers allowance. Carer's Allowance on its own is below the taxable threshold, however if combined with other sources of taxable income such as occupational or personal pensions or part time earnings the total amount is over the tax threshold the carer will pay some tax.

To be eligible for Allowance the carer needs to meet the following criteria:

- Be caring for someone who receives a qualifying benefit, these include:
 - > Middle or high rate of the care component for Disability Living Allowance (DLA)
 - > Either rate of the daily living component of Personal Independence Payment (PIP)
 - > Either rate of Attendance Allowance (AA) or Constant AA of the normal maximum rate paid with Industrial Injuries or War Pensions Scheme
 - > Armed Forces Independent Payment (AFIP)
 - Look after someone for 35 hours or more each week (cannot average out the amount of hours over a number of weeks). A carer is able to take a break from caring for any reason for up to four weeks in every 26 weeks and will still be paid Carer's Allowance, the carer is able to go abroad for this break. The carer is not able to add up the amount of hours they spend caring for more than one person to make up the 35 hours. A carer is only eligible for carers allowance for one person even if they care for more than one each for 35 hours or more. If 2
- people are providing care for a person each for 35 hours or more per week only one of them is able to claim carers allowance. The make-up of the hours spent caring may include:
- > time spent physically helping the person
 - > time spent 'keeping an eye' on the person, e.g. preventing them coming to harm by walking out of the house
 - > time spent doing practical tasks for them, e.g. cooking
 - > time taken doing practical tasks, even if these are not done in the presence of the person being looked after, may also count (for instance, if a carer looks after someone who visits them regularly for the care they need, time spent preparing for the visit or cleaning up afterwards should count)
- Be aged 16 or over.
 - Are not in full time education. Although the meaning of full time education can differ, full time education is likely to be:
 - > When the university, school or college describe the course as full time
 - > There is a requirement to do 21 hours a week or more of study
 - The Carer does not earn over £128 a week (after deductions)
 - The Carer satisfies the UK presence and residence conditions by meeting both of the following conditions:
 - > have been present in Great Britain (which for this purpose also includes Northern Ireland) for 104 weeks out of the 156 weeks before claiming (two out of the last three years)
 - > Must be habitually resident. There is no precise legal definition of 'habitual residence'. Relevant factors are where you normally live, where you expect to live in future, your reasons for coming to this country, the length of time spent abroad before you came here, and any ties you still have with the country where you have come from.

Due to overlapping benefits rules a carer cannot usually be paid Carer’s Allowance if you receive one or more of the following benefits:

- State Pension
- Contributory Employment and Support Allowance
- Incapacity Benefit
- Maternity Allowance
- Bereavement or widow’s benefits
- Severe Disablement Allowance
- Contribution-based Jobseeker’s Allowance

Carer’s Allowance will count as income when means-tested benefits are calculated. However means-tested benefit calculations will include a carer premium, carer addition or carer element. The carer premium is an extra amount of money included in the calculation of Income Support, income-based Jobseeker’s Allowance, income-related Employment and Support Allowance, Housing Benefit and Council Tax Reduction (Rate Relief in Northern Ireland). The carer addition is an equivalent amount paid with Pension Credit. The carer element is an equivalent amount paid with Universal Credit. Being paid Carer’s Allowance when the carer already receives a means-tested benefit may result in the means-tested benefit decreasing slightly.

Claiming Carer’s Allowance will not affect the disability benefit or state pension of the person being looked after but if the person being looked after receives means-tested benefits, a claim for Carer’s Allowance could affect how much they get. For example, if they are receiving the severe disability premium (or severe disability addition in Pension Credit) as part of their means-tested benefits, they will lose this someone is being paid Carer’s Allowance.

The national context

There are 7 million carers in the UK, this equates to 1 in every 10. This is predicted to rise by 2030 by 3.4 million as 3 in every 5 people are expected to become a carer at some time in their lives. 42% of the UK’s carers are men and 58% women. 1.3 million people provide over 50 hours of care per week and over 1 million people care for more than one person. Carers save the economy £132 billion per year which equates to an average of £18,857 per carer.

It is estimated that there are at least 376,000 young adults with caring responsibility aged 16-25. Young adults with caring responsibilities appear to be more than four times more likely to drop out of their college or university course than their peers as 56% of young adults in education advised they were struggling because of their caring role. Children are not exempt from caring. The average age of a young carer in the UK is 12, with some children as young as four undertaking a caring role. Many young carers remain hidden for a number of reasons, including loyalty to family, stigma, bullying and not knowing where to go for support. 68% of young carers are bullied in schools.

In a survey by the Carers Trust, it was reported that only half of young carers have a designated person at school who recognises that they are a carer and provides support. Reportedly young carers on average miss or cut short 48 school days per year because of their caring role.

One in 5 people aged 50 – 64 are carers in the UK with 65% of older carers (aged 60-94) living with long term health problems or a disability themselves. One third of older carers advise that they have had to cancel treatment or an operation that they were meant to have due to their caring responsibilities.

The local picture

The total population of Hull is 259,778. The number of known carers is 23,636 which means 9.22% of the population of Hull are carers. 43% are men and 57% women which is in line with the UK demographic. 53.3% of carers provide an average of 1 – 19 hours per week. 15.3 % provide between 20 and 49 hours per week and 31.3% provide 50 plus hours per week.

79% of carers in Hull are of working age, 2% are young carers aged between 0 and 15 years and the remaining 19% are aged over 65. Of those that are of working age 60% are in employment with 34% in full time employment and 20% working part time. The remaining 6% are self-employed, 4% full time and 2% part time.

67% of carers in Hull describe their health as either very good or good and 24% advised their health was fair. 9% advised that their health was either bad or very bad.



3. Hull's Current Offer

The Care Act 2014 places a duty on Adult social care to offer an assessment to all carers. The carer has the right to a carer's assessment even if the person being cared for declines an assessment of their needs. In the case of carers, eligibility depends on the carer's situation. The carer will be entitled to support if:

- they are assessed as having needs that meet the eligibility criteria
- the person they care for lives in the local authority area

Regardless of whether or not a carer is eligible for public money from the local authority, Hull City Council and its partners are committed to supporting each and every carer to:

- Have access to the information and advice that they need and want to support them in their caring role
- Maintain and develop their health and wellbeing

In order to achieve these things the council and its partners commission City Health Care Partnership CIC (CHCP) to deliver a Carers Information and Support Service (CISS). This aims and objectives of this service are detailed in appendix A.

In September 2019, 2 new roles within CISS were established. The first of these roles was Employment Support Worker whose remit is to work with employers in Hull to support them to support carers. This role includes:

- Encouraging a more flexible approach to working where needed for those in a caring role

- Help to identify carers within their workplace
- Offering advice and support to employed carers and instant access to the CISS
- Offering a service to carers within their place of work and developing in house carer support

The 2nd role is of Hospital Liaison Worker based across Hull Royal and Castle Hill Hospitals. The aim of this role is to offer a preventative approach to carers giving advice and information to carers at the point of them becoming a carer. The role works closely with wards and develops a network of carer's champions to support the ongoing identification of 'hidden carers'.

CISS have also developed a carers networking forum which supports those carers who have taken on the running of local carers groups often whilst still carrying out a caring role. Bi-monthly meetings are hosted and other services who could support these groups are invited. During Covid-19, these have been run virtually as has the majority of the support offered to comply with social distancing regulations and have been well received.

The CISS administers the partnership's direct payments for carers and supports in the care and support planning process. The use of these funds are able to be spent in a way which will meet the carer's identified outcomes as a result of a carer's assessment. These could include options such as equipment for hobbies, short breaks, memberships at leisure centres, days out and spa days which provides respite from the caring role.



Additional respite support is available to carers via the Direct Payments for carers that has been developed in partnership with Age UK. This is a block purchase arrangement which allowed the joint development of a carers support package for carers aged 50 plus. The CISS signposts individuals to a varied menu of activities at Age UK Hull which was reflective of the outcomes identified through the carers assessment.

Furthermore a block purchase of packages through Butterflies Hull (Dementia Support Groups) has been developed which allows carers the option of attending the groups held by Butterflies Hull cost free. This support combats social isolation and provides peer support for both carers and people who are cared for.

Hull City Council is responsible for the completion of statutory carer’s assessments. These assessments are an intervention in its own right. Social care workers undertaking these assessments will support individuals to help address isolation and loneliness, develop skills and abilities to support them in their caring role and enable access to the voluntary and community sector as much as possible. Part of this role involves introducing carers to the Connect to Support (CtS) and the Connect Well (CW) service. Connect Well and Connect to Support also link with the Primary Care Networks social prescribing workers and the health and wellbeing teams.

The CtS is the adult social care information and advice web offer. It includes a wide array of coproduced information and advice for people who use services and their carers. It provides a directory of community and voluntary services available within Hull.

The CW service focuses on providing alternatives to medical interventions in the primary care sector and will also signpost to the CtS service. The CW service has wellbeing coordinators who help people who are at risk of being lonely and isolated

to identify what services may be of use to them and support them to access these. The CISS network into these arrangements with specialist information, advice and focused support for carers.

A Carers Card was introduced last year which provides three functions:

- It establishes that the person carrying it is providing a caring role
- It gives the carer access to a discount and concession scheme with local businesses. This aims to improve the carers’ health and wellbeing by giving them access to opportunities to take time for themselves through discounts for leisure facilities, hairdressers and cafes to name a few
- It includes a contingency management service where should the carer fall ill, end up in hospital or be unexpectedly unable to carry out their caring duties the card identifies them as a carer. This informs professionals that action is required to ensure that the cared for needs are met while the carer is unable to do so. Important information is held about the carer and the person they care for preferences and wishes including who to contact in an emergency or what support will be needed in the interim
- The card also enables primary care to identify carers and offer more flexibility around home visits and with choice and/or priority of appointment.

When the Carers Card was launched this was not on a large scale and there is a belief that many carers and professionals may not be aware of this. Due to this it would be beneficial to relaunch the Carers Card in conjunction with the launch of the Carers Strategy to ensure this is more widely introduced.



4. Impact of Covid-19

The recent Covid-19 pandemic has only highlighted the difficulties faced by the millions of people who provide unpaid care every day. Prior to Covid-19 it was estimated that 7 million people provided unpaid care. Since the pandemic, Carers UK have estimated an additional 4.5 million people are now caring for older, disabled or seriously ill relatives or friends. A recent report by Carers UK “Caring Behind Closed Doors” (April 2020) found 70% of carers are providing more care than before. Over a third are providing that care because of the closure or reduction of local services. Carers were already under pressure before, but now over half (55%) advised that they were feeling overwhelmed and worried they would burn out.

Unpaid carers are fighting the same battle as care staff and many of our NHS workers, yet they are doing it behind closed doors and with far less recognition. The lack of recognition for unpaid carers and limited understanding of the support they offer was evidence from the shortage of clear

guidance provided by the government and the deficiency in the provision of Public Protection equipment (PPE). Many carers felt confused by the guidance available and were unable to access PPE in order to keep themselves and their loved ones safe.

Within Hull the feedback provided from carers has been mixed. During the months of April and May the number of referrals to the council reduced nearly by half in comparison to the predicted volume. Additionally day service support ceased and respite care was only provided in urgent circumstances where there was no other option. Some people chose to cancel their existing packages of care in order to prevent people entering the house due to the risk associated with this. As a result the amount of informal care being provided within Hull has increased significantly. From a survey carried out by the Carers Information Support Service (CISS) it was reported that although carers appreciated service contact via telephone throughout lockdown and would like this to continue they missed the face to face contact with services and were looking forward to the return of this provision. Carers identified a real need to have ‘time for themselves’ and reported feeling socially isolated in their role.

5. The Strategy



What is it?

This Strategy sets out the priorities that will shape the delivery of support for carers from 2020 – 2025. It will set out a case for investing in carers services and outline what needs to be done by Hull City Council and its partners. The strategy has been developed by Hull City Council alongside carers and a range of stakeholders as a joint approach to supporting carers. The strategy builds on the national direction set out in the NHS long-term plan 2019, The Department of Health and Social Care Carers Action Plan 2018 – 2020, the Care Act 2014 as well as local issues to develop a strengths based approach to carers support. The National Institute for Clinical Excellence (NICE) guidelines advise that good quality consistent support helps to address the impact of the caring role and provides benefits to health, wellbeing and resilience. This support can also have a positive impact and enhance the life of the person being carer for and help to reduce admissions to hospital and support with earlier discharges. The guidelines raises the concern that the quality of this support varies widely across the UK and local systems can be difficult to manage. This strategy sets out to ensure that the quality of the support available in Hull is consistent and of good quality. It is a commitment to partnership working to develop a carer friendly society which will empower and support carers to fulfil their caring role whilst maintaining health and wellbeing.

How was it developed?

The Integrated Carers' Partnership Board (ICPB) met in July 2018 for the first time. It had 2 primary functions, these were:

- Create an integrated carers' strategy
- Oversee implementation of the agreed strategy

The ICPB meet bi-monthly and included membership from the following organisations and individuals:

- Hull City Council
- CHCP - Carers Information Support Service (CISS)
- Humber Teaching Foundation Trust
- Safeguarding Board
- Carers x6 including young carers
- NHS Hull Clinical Commissioning Group
- Public Health

The objectives of the ICPB are:

- Develop a shared-system wide strategy for carers in Hull City Council
- Identify and agree strategic priorities and key operational issues
- Develop a shared action plan across partners to address identified issues
- Review and monitor progress of the agreed action plan

The ICPB set up a major 'system wide' consultation process to engage with carers in Hull. The consultation process focused on gathering responses to 3 key questions, these were:

- What information, advice and support is currently available for specific groups of carers?

- What would specific groups of carers like the information, advice and support to be in the future?
- What specific needs do the groups of carers have?

The identified groups of carers were:

- Carers for people with profound and multiple learning disabilities (PMLD)
- Carers for people with a learning disability
- Young Carers
- Carers for young people in transition to adult social care from children's services
- Carers for people at the end of life
- Carers for people with dementia
- Carers for people with mental health problems
- Carers for autistic people
- Carers in employment

A project lead was agreed for each carer grouping and project support was provided by Hull City Council's corporate programme support team. Contact was established with each of the identified groups of carers and with individual carers who could help us understand the issues, wants and needs of carers using the 3 key questions, specified above, and a general framework.

In addition, the Differently Abled Event In February 2019, hosted by City Health Care Partnership CIC (CHCP), NHS Hull Clinical Commissioning Group and Hull City Council was used to make contact with over 70 individual carers. As well as interviews with these carers, a "wall of thoughts"

was used to gather the views of people who did not necessarily identify as an informal carer.

Our vision

The aim of this Strategy is to develop and maintain support arrangements for carers in Hull to live healthy, independent and meaningful lives whilst fulfilling their caring role effectively. Through jointly commissioned, integrated support; good quality information, advice and services will be provided with a focus on prevention and early intervention enabling the carer to feel empowered, recognised and valued for the role they undertake. Carers will be able to access flexible, tailored and responsive support to ensure that their caring role is manageable and balanced alongside other aspects of their lives. It is the vision of Hull City Council and its partners that as a result of the implementation of this strategy all carers in Hull will have improved overall health and wellbeing.

Our priorities

As a result of the consultation, some co-production with different carers groups and through the ICPB the following 4 priorities were identified to meet this vision:

- Integrated information and advice
- Jointly commissioned integrated prevention and early intervention
- Shared integrated respite activity which supports specific situations
- Shared collaborative statutory activities

These will be outlined in more detail in the next section.

Delivering the Strategy

Priority 1 – Integrated information and advice

A key theme across all the carers group is the need for relevant information and advice on a variety of topics. This mirrors the “Supporting adult carers” Nice guidelines that identifies information and support for carers as the first of its key recommendations. The Nice guidelines advises that in order for this information and support to be effective and useful it needs to be consistent, up to date, plainly worded, clearly presented, free from jargon and provided in small, manageable chunks.

The consultation identified some specific areas in which carers feel they are lacking access to information. These are specific medical conditions, what being a carer means, what help and support is available, clearer information on finances, particularly in relation to accessing benefits such as personal independence payments, continuing health care entitlements, accessing statutory social care and health funding and provisions and understanding direct payments, personal health budget and charging policies. Carers also identified a need to be kept informed around the amendments to the Mental Capacity Act around the changes to issues of consent from 16 years of age and the role of Court of Protection and Liberty Protection Safeguards and how these will impact. This information needs to be provided in a range of formats and languages to meet the carer’s needs and preferences. Additionally to providing information in a written or verbal form, CISS will provide quarterly carer conferences which will be themed and aimed to target specific carer groups for example, parent carers, autism, mental health etc. This will enable information and advice to be disseminated to large groups of professionals and carers but also enable an opportunity to network with other people in the same situation and share

good practice/good news stories.

The feedback particularly from young carers indicated a need for the more up to date use of social media in presenting and disseminating information to and about carers. This echoes the NICE Guidelines, which recommends the need to link the sharing of information with local and national online and digital resources such as websites, forums and social media. This will enable wider engagement with carer communities and makes the information more accessible in a society which is becoming more and more digitally capable.

The Hull Local Offer provides information on the support available to people aged 0 – 25 with special educational needs and disabilities and their families. Hull Connect to Support is the local advice and information service for people living in Hull. It was identified by the people consulted that the link between these two services needs to be improved with more shared content across Children’s and Adult’s departments within the council. Forging stronger links between these departments and schools will improve the support available to carers of young people who are likely to have eligible adult social care needs once they turn 18.

More information and advice is required about the support services that are available to autistic people, such as tenancy support services, employability support and clearer referral processes. Link work is required with the Autism Partnership Board to prevent duplication as these may/should be areas of work currently being considered/developed in this forum.



Priority 2: Jointly commissioned integrated prevention and early intervention

Ensuring that carers are aware of preventative measures available to them in Hull such as flu jabs for people with long term conditions or for those over 65 years of age, shingles jabs for 70 and 78 years old and lung checks for people who used to or currently smoke aged 55 – 75 and how to access these will prevent illness and potentially catch problems before they become untreatable. This will assist carers to remain healthy and well and support them to remain able to continue in their caring roles.

Additional work is needed with front line support services such as fire, pharmacy, GP's, community nurses, early intervention social care as well as employers to enable them to recognise people who are undertaking an informal caring role. Training is required to support these identified groups of people to not only identify carers but to help people recognise themselves as carers when this is not something they naturally identify with and access the information and support available to them. The Nice guidelines recommend that to support to identify carers every opportunity should be utilised. These opportunities include GP appointments, flu jab appointments, outpatient appointments and social care and other assessments.

The need to identify carers should not be restricted to those who are struggling to manage but needs to focus on identifying all carers with a focus on early intervention and support to prevent a crisis point being reached in the future. Hull City Council and its partners are committed to developing the See and Solve service (Hull City

Council's first point of contact for people who use services and their carers) and improving the links between this service and the CISS. The aim of this development work will be to enable better identification of carers, better provision of pertinent information and advice for carers and accurate and useful signposting to relevant support networks and early interventions.

There is an identified need for the development of peer support networks that cater for the different categories of carers. Peer Support is widely considered to reduce a sense of isolation, enable the sharing of information and advice and provide emotional support. The feedback received from the consultation indicated that carers in Hull are not aware of what is available in terms of peer support groups and networks. There was a strong desire for "help to help themselves" as they are expert partners and with support and guidance from professionals and others in a similar position to them are best placed to provide the best care to their loved ones.

A requirement for additional training for key primary and secondary care staff particularly around supporting people with autism or learning disabilities was highlighted by the consultation. Staff need to be clear on the difficulties that carers and those they care for experience and have a good understanding of what support is available and provide suitable advice and information to prevent needs from escalating to crisis point. The introduction of a health and social care 'navigator service' could address this which is recommended by the Nice guidelines which suggest "a carer champion" within a range of settings such as GP surgeries, hospitals or workplaces who takes on the task of supporting and speaking up for carers.



Priority 3: Shared integrated provision which supports specific situations

Within the consultation it was identified that people who care for people at end of life are often at risk of social isolation and potential health concerns following the death of their relative. The main focus has been on the person at end of life and the carer neglects their needs and the above mentioned risks are not identified in a timely way. Post death many services step away leaving the person at an increased risk of isolation and ill health. Information and advice is required to carers who are no longer taking on this role following a bereavement to ensure that they have a clear understanding of what ongoing support is available to them and how this can be accessed. This is in line with the NICE Guidelines which identifies the need for specific support for carers during end of life care and after the person dies as one of its recommendations. This includes supporting the carer to plan for their own future when the person they care for dies and discussing with them how to address their own support needs.

Another of the NICE recommendations relates to the importance of supporting carers to stay in, enter or return to work, education or training. For those who wish to continue working or training alongside their caring role should have access to tailored advice and support on how to balance these roles in a way which is manageable and does not impact in a negative way on their own

health and wellbeing. Carers who wish to return to work, education or training after the person they care for has died may need support with this. The NICE guidelines recommends that services need to be able to provide knowledgeable and expert advice and support carers to recognise that the skills they have gained through their caring role are transferable and to support them to describe these skills in a way that will appeal to employers. A policy objective developed by partners of this strategy is to reduce the number of carers leaving employment as a result of their caring role. The strategy commits to providing better access to publicly funded services such as home care and day opportunities, for those that are eligible for support under the Care Act which will in turn support those who are in caring roles.

A specific area of need identified as part of the consultation process was in relation to the ability for carers to access short-term support both inside and outside the home environment in a way which is quick and easy. The NICE guidelines advise that carer's breaks should meet the carer's needs in terms of timing, duration and frequency. It is particularly important that these breaks from the caring role are wherever possible planned for in advance at regular intervals in order to reduce the risk of carers getting to the point of crisis where they are no longer able to manage. Open and honest conversations are required with carers to inform them about the support available to them and to encourage them to accept and utilise this support early and to understand the benefits of this. Social Care Institute for Excellence (SCIE) advises that the quality of support available to



carers is vital as it strongly influences whether carers will take a break. A poor experience can put them off. Carers want time to build up trust with the service provider so they can be confident the person they care for will have a good experience. Consistent professional support was identified as important to carers particularly those who are likely to have a long term caring role as it enables trust to develop and carers to feel confident when asking for help.

Carers also identified the need for more accessible arrangements to access equipment and adaptations both for themselves and for the person they care for. Depending on the type of equipment this may be provided by the local authority or health and routes to access this can differ which can make the process complicated and difficult to navigate for carers who already have a lot to deal with. In order to make this easier and simpler a more streamlined process is required.

Carers, particularly those new to the role of informal carer, may require short-term support to help them to develop the skills and expertise they require to take on this role effectively. Feeling confident in their ability to complete the various tasks associated with the role can reduce the impact this will have on their health and wellbeing. In addition short-term support to the cared for to support them to regain skills they once had but have lost will maximise independence and wellbeing and reduce the ask on the carer. Often when a person receives a diagnosis there is an assumption that they will be able to manage and the opportunity to discuss how they will manage or who they have to support them is not utilised. If they are accompanied by someone to their

appointment it is assumed that that person will act as their carer going forward but this is not checked and no conversations are had about what both the looked for and the carer can expect as a result of the diagnosis. Work needs to be done with health professionals responsible for giving diagnoses to make the most of the opportunity and have open, honest and informative conversations with the person and their carer around what the future will look like, what support they may need and details of the services and support that may be available to them and how to access these.

Consultation with carers of people living with dementia identified a requirement for support provision on discharge from hospital to prevent the need for residential care. The Alzheimer's Society advises that the provision of intermediate care in the form of a range of services and equipment can help people regain some or all of their independence after a stay in hospital and reduce the need for long term support or a readmission. Intermediate care can be provided either within a residential rehabilitation unit or within the person's own home. A key proposal to support in these scenarios is to deliver a hospital dementia discharge service working closely with a community carer resilience service.

Carers of people with autism identified that they often struggle to get health care for the person they care for particularly at critical moments such as admission to hospital. An early intervention service providing support at this time would be beneficial. Partnership working with the Autism Partnership board is required in order to establish what this service would need to look like for it to be effective.

Priority 4: Shared collaborative statutory activities

The respite care market is fragile, after years of austerity the funding available to purchase quality respite provision is in short supply, and providers struggle to recruit well trained experienced staff due to relatively poor wage levels compared to competing sectors such as retail and hospitality. The result of this means that it can be difficult to find suitable respite placement options for people who use services. This is an issue widely recognised by both the CCG and the council, both regionally and nationally. Hull City Council and the CCG will work together to develop the respite care market to ensure that good quality care and support is available to those that need it.

A more comprehensive Personal Assistant (PA) register is needed in Hull. The register will include a list of approved PA's who have chosen to become a paid carer as a career pathway. PA's require the necessary caring skills and qualifications to meet carer needs whilst providing a caring and responsive carer support role. An approved list of these people will give carers and their cared for access to people who they can feel confident in hiring to provide high quality care. The administrative support provisions for carers who receive statutory personal budgets also needs to be enhanced to enable carers to act on information and advice given to them and make choices that enables them to respond quickly to changes in circumstances.

Hull City Council Adult and Children's services and schools need to ensure that a review of the quality of formal carers assessments both for adults and young carers to ensure that these are meeting the needs of carers and that the plans put in place as a result of these assessments are appropriate and effective. Further reviews are required to ensure that transition plans for young people moving onto adulthood are of good quality and that the support required to make these transitions smooth and positive is in place.

Improving the overall health and wellbeing of carers

Carers deliver health and wellbeing in ways that the statutory sector cannot. This is because the care and support provided by carers is highly

personal; it is 'organic', formed out of familial relationships and friendship bonds that paid carers services are unable to replicate. Partners in this integrated carers strategy are determined to recognise the value of the contribution made by carers in Hull and to increase carers wellbeing over the lifetime of this strategy and beyond.

The Nice guidelines identifies support during changes in the caring role as one of its key recommendations. These changes can include transitions into or out of the caring role as a result of end of life, admission and discharge from hospital and admission to residential care. Other changes may relate directly to the carers own situation such as managing a transition into or out of employment due to retirement or inability to maintain a job alongside the caring role. In order to manage these changes information and emotional and practical support is required to help carers prepare for and adjust to these changes.

Through the consultation with carers the kinds of provisions that were identified as supporting the wellbeing of carers were:

- Carers breaks both within and out of the home
- Replacement care services to support alongside the care the informal carer is providing such as home care, day opportunities
- Access to direct payments for carers (to employ personal assistances or access creative ways of supporting the cared for and carer to meet their outcomes)
- Emergency response provisions for carers
- Early interventions at known times of stress and difficulty for carers
- Early identification of carers and the provision of information and advice around the caring role and the support that is available
- Provision of any necessary training, support or specialist advice required by the carer to ensure that they have the skills and knowledge to carry out the role
- A well conducted carer's assessment that is jointly produced with the carer assisting them to reflect on what matter most to them and to identify what will enable them to achieve this

Appendix A

The Carers Information and support service (CISS)

Aims and objectives of service

To improve the quality of life for carers in Hull, helping them sustain their caring role, and enhancing their ability to enjoy a life of their own through the provision of a range of person, coordinated and outcome focused services.

The Carers Service will be delivered on behalf of Hull City Council and NHS Hull CCG.

The key priorities for the carers' journey and to improve the quality of life for carers are:

- Think Carer, Think Family; Make Every Contact Count
- Support what works for carers, share and learn from others
- Right care, right time, right place for carers
- Measure what matters to carers
- Support for carers depends on partnership working
- Leadership for carers at all levels
- Train staff to identify and support carers
- Prioritise carers health and wellbeing
- Invest in carers to sustain and save
- Support carers to access local resources

Service description/care pathway

Early intervention and prevention are key elements of a Carers support pathway. Carers are to be supported early in the support pathway through understanding the diagnosis and condition of the person they care for, by being supported with appropriate coping strategies, skills and knowledge to enable them to support the person cared for. And at the same time ensuring that they are aware of sources of information and advice, and that they are linked into support networks for ongoing and any future support needs.

A full assessment of needs will be offered to all carers who are identified and engage with the service which will include support with self-assessment. Findings from the assessment will form the basis of any agreed carer support plans developed with the carer's wellbeing and best interests in mind.

The service model is to provide a comprehensive programme for the identification, assessment, care planning and access to relevant support services that best meet the needs of adult carers in Hull. An outreach model, with a central hub, will be used to maximise identification of hard to reach carers across the city.

Carers are to be encouraged to maintain their health and have regular health checks and close working with GP practices and hospitals will be necessary to support this.

The service provider will be required to work with mainstream services such as health and social care services, and required to ensure carers are identified early in their caring role and are signposted to relevant support.

During the Carers Pathway timely preventative support is to be provided which can help sustain the caring role. This is to include breaks, peer support and access to Carers Support Groups.

For carers in crisis and where there is a possibility that the caring role may break down a response service is to be provided. This may include the provision of a period of intensive support to the carer for a short period of time (maximum six weeks) in order to enable the carer to continue to care, where they wish to do so.

For carers caring for people at the end of their lives, appropriate carers support is to be provided including the identification of short break opportunities, counselling and peer support.

Identify hidden carers and undertake outreach support

The provider is to identify, learn and report to local commissioners where cases of 'hidden carers' are apparent locally and provide these carers with access to appropriate support to continue their caring role. The provider is to work with carers from communities which have traditionally been seen as hard to engage e.g. communities for whom English is not a first language, carers from rural communities, mental health carers, carers of people with learning disabilities and or autism and carers of people with substance misuse issues.

The service is to provide regular episodes of outreach support work within GP surgeries, hospitals, and with healthcare professionals, faith organisations, places of further education and leisure centres to identify carers and ensure they are signposted to appropriate support and in doing so ensure that carers are provided with the necessary information to manage their own health and wellbeing.

Provide a carers response service for carers in crisis

Ensure an intensive support service is provided to carers who are in crisis or near breakdown for a maximum duration of six weeks, following an assessment of their need. The provider is to record the type of support provided, the impact of the support provided, and report on the outcomes achieved for the carer.

Safeguarding

The Council/CCG has agreed with other statutory authorities a multi-agency policy and procedure to protect adults at risk of abuse. The provider shall follow the policy and procedures if abuse is

identified or if the provider has grounds to believe that abuse may have taken place.

The provider shall have in place its own internal guidelines to protect adults at risk of abuse. These must be consistent with the Multi-Agency Policy and Procedures.

Develop and maintain a carers register

To maintain on behalf of the Council and the Clinical Commissioning Group a Carers Register. This register will contain carer's contact details, their date of birth, their relationship to the person cared for and the cared for person's service user group.

Carers must be informed and their (and patient) consent sought that their information will be shared with the council officer responsible for monitoring the service on behalf of the council and the Clinical Commissioning Group. Carers must be informed that this is as part of the monitoring of the service and information will be used to inform future commissioning decisions around support for carers.

The register is to be reviewed and updated regularly and details relating to carers who no longer have caring responsibilities must be removed within six months of their caring role coming to an end.

The register should clearly reflect the number of carers who have received information, advice or a service from or through the Carers Support Service, and identify the type/types of service provided.

The register is intended to ensure that carers receive accurate up to date information on services and support available and will be used to ensure that carers have a voice in the way future services are planned, developed and commissioned.

The register will provide a clear profile of local carers and will be linked to a record of support provided to the carer and outcomes achieved. This information will be used to inform future commissioning decisions and will therefore need to be made accessible to commissioners.



Support for carers to remain or return to employment

The provider is to provide support and information to Carers to access education and training. The provider is to work with Job Centre Plus, universal services and local training providers and signpost carers to appropriate support.

Carers newsletter

The provider is to provide a newsletter to all Carers on the carers register a minimum of twice a year. This is to be provided electronically where possible.

This should include up to date and relevant information from partner agencies on new developments and forthcoming events.

Referral processes

Carers are able to have open access to the service by telephone, email, drop-in or prior appointment and can access CISS via 247111 if required.

Care support plans will have clear documentation that set out the summary of carer's eligible needs and the outcomes they will aim to achieve. Adult carers who engage with the service, and upon completion of an assessment and the support planning process, will have access to appropriate service(s) listed below delivered by the Service Provider(s):



Manage and administer direct payments to eligible adult carers.

The intention is to give carers more independence and choice in their support arrangements. Local Authorities offer the option of Direct Payments for eligible carers who are assessed as needing extra support. The Provider will be required to raise awareness of the service to identify potential carers and administer a system of one-off payments to provide a short break from caring, following an assessment of the carer's eligibility. The eligibility criteria for support is set by statute and the right to a Direct Payment is set out in statutory regulations which the Provider must follow. Direct Payments give greater independence and enable carers to pay for activities that will improve their general health and wellbeing.

Carer's assessment

First Stage Carers Assessments will be a gateway to personalised outcome focused support for carers. This process is to improve responsiveness to carers, reduce waiting times for statutory assessments, direct carers promptly to support and minimise reliance on statutory services.

The service provider is to use a triage system to ensure a balance is struck between early intervention and prevention work, supporting those in the greatest and promote self-service for those who are able. A log of all carer contacts made is to be kept.

The service provider will act as a first stage assessor for and undertake a carer's assessment with new carers accessing the service to determine the carer's needs. The provider will

work closely with the local council to avoid duplication of assessments and plan appropriate support for carers.

The provider will use existing assessment tools and processes, including where possible self-assessments; with a view to developing a future model of assessment in partnership and in agreement with the Council.

Provide respite and short break provision

This will include giving support to the person needing care at a suitable venue enabling the person's carer to have a short break, facilitating joint activities with carers and cared for people together, supporting the cared for person in their own home so the carer can have a short break, consultation with carers to understand the most effective method for them to take a break. This service will cover normal daytime working hours. It does not offer extended periods of support (e.g., overnight, holidays, regular periods of support, etc.) though it may identify the need for these via assessment and may fund this through the administration of small grants. It will facilitate access by signposting to associated Providers who offer longer-term break provision.

Free training

To include: moving and handling, basic psychology and mental health, suicide prevention, first aid, general healthcare, risk management and managing personal finances. Other relevant training opportunities should be provided as identified and agreed.

Integrated Carers Strategy 2020 – 2025

“A life not a service”

