

Draft - Carer Friendly Southampton

Carers do all this and more for family and friends who are older, ill or have a disability...



...all while trying to maintain a life of their own.

The infographic features a central blue silhouette of a person standing on a gear. Six colored arrows point outwards from the person to six circular icons, each representing a different aspect of carer support: Practical support (purple circle with a person at a washing machine), Emotional support (pink circle with speech bubbles), Personal care (red circle with a person in a shower), Financial matters (orange circle with a calculator and coins), Physical help (green circle with a person in a wheelchair), and Administer medicine (teal circle with a pill and syringe).

PANEL MEMBERSHIP – 2020/21

Councillor Savage (Chair)
Councillor Prior (Vice-Chair)
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SOUTHAMPTON
CITY COUNCIL

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Chair's Introduction



Councillor Savage - Chair of the Carer Friendly Southampton Inquiry Panel (2020/21)

To be added post 8th April 2021 Inquiry Panel meeting

Carer Friendly Southampton

The Aim of the Inquiry

1. The 2018-20 Carers Action Plan identifies that *'every year, more and more people take on a caring role. The enormous contribution of our country's carers not only makes an invaluable difference to the people they support, it is an integral part of our health and social care system and it deserves to be better recognised.'*
2. The Carers Action Plan, reflecting carers feedback to Government, states that *'too often carers feel they are on their own, do not feel respected, valued and supported for the huge contribution they make. They feel that what they do is sometimes taken for granted and overlooked, which often takes a toll on their own wellbeing. Not only do carers face emotional challenges but they sometimes navigate through complex systems with little formal guidance and direction.'*
3. The national perspective outlined above corresponds with feedback provided about Southampton. Findings from the 2018 National Carers Survey of adult carers identified disappointing levels of satisfaction with the support, or services, carers, and the person they care for, received from Southampton Social Services.
4. Given the contribution made by carers, and the recognition that there is a need to improve outcomes for carers in Southampton, the Overview and Scrutiny Management Committee recommended at the September 2020 meeting, that an inquiry focussing on improving support for carers in Southampton is undertaken by the Scrutiny Inquiry Panel.
5. The set objectives of the inquiry were:
 - a. To review progress being made in Southampton to support carers.
 - b. To identify good practice being employed to support carers elsewhere.
 - c. To identify what initiatives could work well in Southampton to help support carers.
6. The full terms of reference for the inquiry, agreed by the Overview and Scrutiny Management Committee, are shown in Appendix 1.

How the inquiry was conducted

7. The Scrutiny Inquiry Panel undertook the inquiry over 6 evidence gathering meetings. At the start of each meeting the Panel received feedback from carers ensuring that the views of adult carers, parent carers and young carers were represented.
8. In addition to hearing from carers, the Panel received information from a wide variety of organisations. This included Carers UK, NHS Providers in Southampton, Portsmouth City Council, Surrey Heartlands ICS, NHS England and Improvement, the Department for Work and Pensions, The Children's Society, No Limits, Carers In Southampton, as well as officers from Southampton City Council and NHS Southampton City Clinical Commissioning Group. A list of witnesses that provided evidence to the inquiry is detailed in Appendix 2.
9. The key findings, conclusions and recommendations from the inquiry are detailed succinctly later in this report.

10. Members of the Panel would like to thank all those who have assisted with the development of this review, in particular the following who have provided the Panel with invaluable advice throughout the inquiry:
- Adrian Littlemore, Senior Commissioner, Southampton Integrated Commissioning Unit;
 - Kirsten Killander, Service Development Officer, Southampton Integrated Commissioning Unit.

Introduction and Background

Definition of a carer

11. In her presentation to the Inquiry Panel, Anne Meader from Carers Together, referenced that:
‘There is no single, simple way of defining a carer because all carers are different individuals supporting different people with different needs.’
12. The NHS consider carers to be anyone, including children and adults, who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid.
13. Carers UK defines carers as people who provide unpaid care by looking after someone who is older, disabled or seriously ill.
14. The Children and Families Act 2014 Section 96 defines a young carer to be
“...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).”
15. A parent carer is someone over 18 who provides care to a disabled child for whom they have parental responsibility.

National Context – Number of carers

16. The 2011 Census indicated that there were around 6.5 million unpaid carers in the UK, with 1.3 million being over 65. Most carers were aged between 50 and 64 but people aged 65 and over made up a higher proportion of carers (19%) than in the population as a whole.
17. Carers UK estimate that the number of carers has risen since the 2011 Census and that there were up to 9.1 million unpaid carers across the UK before the COVID-19 pandemic, providing everything from a few hours of support a week to intensive and complex round the clock care.
18. The Carers Week 2020 Research report¹ identified that the pandemic has resulted in millions of new carers – 4.5 million new to caring since the start of the pandemic, 2.8 million of whom are juggling work and care. The estimated 13.6 million unpaid carers is equivalent to one in four adults in the UK.
19. The 2011 Census found there were 166,000 young carers in England aged 5-17 years. Research carried out by BBC News and Nottingham University now estimates that there could be up to 800,000 young carers in the UK². That would represent 1 in 5 in every classroom.

The rising value of carers support

¹ Carers Week 2020 Research Report: https://www.carersuk.org/images/CarersWeek2020/CW_2020_Research_Report_WEB.pdf

² <https://www.nottingham.ac.uk/news/pressreleases/2018/september/children-england-care-sick-family.aspx>

20. In 2015 Carers UK published a report that valued the contribution made by carers in the UK to be £132 billion per year.³ The figures mean that, in 2015, the value of the contribution made by the UK's carers saves the public purse enormous sums every week, day and hour of the year:
- £2.5 billion per week
 - £362 million per day
 - £15.1 million per hour
21. Given the substantial increase in carers due to the COVID-19 pandemic it is likely that this figure will have risen significantly.

Outcomes for carers - Health

22. Caring can have a significant impact on a carers health, with carers often finding that both their mental and physical health are affected. The NHS GP Patient Survey 2019 showed that carers' health and wellbeing is worse than the general population, 61% of carers reported a long-term condition, disability, or illness compared with 50% of non-carers.
23. Research by Carers UK into carers' health and wellbeing found that most of those providing substantial care had faced mental ill-health and physical ill-health as a result of caring. Specifically, 6 out of 10 people (61%) say their physical health has worsened as a result of caring, while 7 out of 10 (72%) said they have experienced mental ill health.⁴

Outcomes for carers - Education

24. Evidence shows that being a young carer can impact on attendance, attainment, personal development and welfare.
25. Research has identified that 27% of young carers (aged 11–15) miss school or experience educational difficulties.⁵
26. Using the Longitudinal Study of Young People in England data, research conducted by The Children's Society (2013) found that on average, young carers achieve nine grades lower overall at GCSE than their peers (an average of one grade lower across all subjects).

Outcomes for carers - Wealth

27. Despite the valuable contribution they make to society many carers face very difficult financial situations due to their caring responsibilities. In a 2019 survey when asked how they would describe their financial situation, almost 2 in 5 (39%) carers said that they were struggling to make ends meet.⁶
28. Carers often find their own income affected by caring, and this can be compounded if their partner or another family member has also had to leave work due to their illness or disability.

³ Carers UK (2015) *Valuing carers – based on 2015 carer projection*

⁴ Carers UK (2019) *State of caring – A snapshot of unpaid care in the UK*

⁵ Dearden, Chris & Becker, Saul. (2004). *Young Carers in the UK: the 2004 report*

⁶ Carers UK (2019) *State of caring – A snapshot of unpaid care in the UK*

29. A 2019 Carers UK report, 'Juggling Work and Unpaid Care', identifies that the number giving up work to care has increased from 2.3 million in 2013 to 2.6 million in 2019. Nearly half a million people (468,000) have given up work over the past two years as a result of caring. This equates to around 600 people every day. Those over the age of 45 were most likely to have given up work to provide care.
30. Specific research into the prospects for young carers identified that they are more likely than the national average to be NEET (not in education, employment or training); more likely to be persistently NEET over 2 years; more likely to be in lower paid jobs than their peers in their early 20s; and, for families with a young carer, the average annual income is £5,000 less than families who do not have a young carer.⁷
31. A 2019 national survey of parent carers identified that 53% of respondents had been forced to give up paid employment. Parent carers also have a high percentage of single-parent families due to pressure and stresses.

The impact of COVID-19

32. As stated previously the COVID-19 pandemic has resulted in millions of new carers. Carers have been hit particularly hard by the pandemic. The October 2020 report from Carers UK, 'Caring behind closed doors: six months on', included the following key statistics:
 - 81% of carers are currently providing more care than before lockdown
 - 78% of carers reported that the needs of the person they care for have increased
 - 64% have not been able to take a break in the last six months
 - 58% of carers have seen their physical health impacted by caring through the pandemic
 - 64% said their mental health has worsened.
33. The results of a Carers Trust survey into the impact of the pandemic on young carers aged 12 to 17 and young adult carers aged 18 to 25 was published in July 2020⁸. They point to a steep decline in the health and wellbeing of the hundreds of thousands of young people across the UK who provide unpaid care at home for family members or friends:
 - 40% of young carers and 59% of young adult carers say their mental health is worse
 - 67% of young carers and 78% of young adult carers are more worried about the future
 - 66% of young carers and 74% of young adult carers are feeling more stressed
 - 69% of both young carers and young adult carers are feeling less connected to others
 - 11% of young carers and 19.7% of young adult carers report an increase of 30 hours or more in the amount of time they spend caring per week.

⁷ The Children's Society (2013): Hidden from View

⁸ Carers Trust (2020) - My Future, My Feelings, My Family

Southampton Context – Number of carers

34. Prior to the pandemic, Carers UK estimated that 1 in 8 people provide unpaid care. Using this ratio, the number of carers living in Southampton, including over 2,000 young carers, is estimated to be about 32,000.
35. Carers In Southampton and No Limits are commissioned by Southampton City Council to provide services for carers. As of October 2020, Carers In Southampton, the provider of the support service for adult carers in the city, were aware of 4,068 carers, of which 2,428 had been in contact with the service within the past 2 years.
36. No Limits, the commissioned provider of support for young carers in Southampton, were aware of 420 young carers and were supporting 80 young carers. The vast majority of carers in Southampton are therefore not known to the commissioned providers of services to carers.

The value of carers support in Southampton

37. The 2015 report from Carers UK, 'Valuing carers', provided forecasts of the value of unpaid care for each local authority in the UK. The value of unpaid care in Southampton, in 2015, was forecast to be £411m per year.

Outcomes for Southampton's carers

38. The 2018/19 National Adult Carers Survey revealed that more than half of carers in Southampton experience financial difficulties due to their caring role, this is appreciably higher than the previous survey in 2016/17.
39. Carer's Allowance provides a measure of financial support and recognition for those who have had to give up or limit their employment because of their caring responsibilities. As of May 2020, there were 3,517 carers in receipt of Carer's Allowance in the City of Southampton and £12.1 million was spent on Carer's Allowance in Southampton in 2019/20 (£67.25 per week is Carers Allowance).
40. The Inquiry Panel were informed by the Co-ordinator of the Southampton Parent Carer Forum that she has seen many parents having to take pay cuts and give up businesses to care for their disabled children.
41. A survey of young carers in Southampton, conducted by No Limits for the inquiry, asked, 'Has your caring role affected your emotional well-being?' Of those that responded 60% replied 'yes'.
42. The following anonymous quotes from Southampton carers provide an insight into the impact that caring has on the outcomes for our carers:

'I had to quit a job I loved & take a job with less hours as my son needs me all the time, I haven't spent any 1-1 time with my husband in 4 years'

'I can get tired at school as my brother has been coughing at night and sometimes I don't get time to do my homework'

'I am very tired and suffering from depression. Caring has drained me and badly affected my arthritis'

'Whenever something is happening with the person I care for, it has a huge effect on my daily life and overall mood'

'I'm not scared to die, I'm scared who will care for my son. I'm exhausted. Household jobs take longer'

'Sometimes I wake up to help my mum, I used to fall asleep at school. If I don't get enough sleep then I am grumpy'

'I had to reduce hours from full time to 4 days a week, so financial cost - huge emotional cost on me balancing work commitments and commitments to the person I care for - feeling I never do either as well as I want to'

'I had a breakdown following the fight I had to get suitable special ed place for my boy whilst trying to sustain a teaching career. I have no childcare options for my lad due to his disabilities, no family nearby to take on any caring role and have had to take at least a £20k cut in salary, ending a 20 year career in teaching.'

The impact of COVID-19 on Southampton's carers

43. A comprehensive review of the impact of the pandemic on carers living in Southampton has not been undertaken. However, information presented to the Inquiry Panel, outlined in the paragraphs below, provides an insight in to the situation in Southampton.
44. Carers In Southampton provided a Keep in Touch service to carers during the pandemic lockdown. Calls indicated that many elderly single parent carers have been hospitalised from burnout.
45. Carers in Southampton's website tracking statistics recorded an acute rise in searches from carers for food support, assisted shopping support, legal advice and hospital parking costs.
46. Parental feedback provided to the Inquiry Panel by the Southampton Parent Carer Forum Co-ordinator included:
 - *'Covid has meant...if I'm completely honest, more trapped....'*
 - *'...everybody is on their knees, but I think parent carers are absolutely on their hands and knees crawling right now. I think we are done... we live on such a finite level of resource and personal resource.'*
47. In a survey of young carers by No Limits, young carers were asked to identify how the pandemic has affected their caring role. The following feedback was received:
 - *'My caring role increased because we had no support/carers coming in to the home.'*
 - *'It has made me really stressed out. My sibling has been having big meltdowns. Feel lonely and low in mood at times.'*
 - *'We are both nervous when going out and my nana can't help mummy as much as normal.'*
 - *'I cannot go out to go to the shops, and we aren't receiving reliable food and income.'*
 - *'I had difficulties in getting medication for both mum/dad and myself. Medication is restricted to pick-up only and only dad has been able to do this outside of working. Mum's anxiety heightened especially before Xmas going into Tier 4. My sister is returning to Uni next week so will revert to being the main carer for mum whilst dad is at work.'*

Legislation and Policy Context

National Legislation

48. Nationally there has been significant work on how best to support carers. A number of obligations have been placed on both social care and health to enable people to care whilst maintaining their own lifestyle, livelihoods, social life and many other important aspects of day to day life and personal wellbeing.
49. Carer specific provisions have been mainstreamed in Government legislation and they were summarised as follows by Emily Holzhausen OBE, Director of Policy at Carers UK in her presentation to the Panel:

The Care Act 2014 - Introduced new rights for carers and new duties for local authorities to provide support for carers. In particular:

- Duty to provide information and advice
- Duty to identify and assess on appearance of need
- Duty to provide services following eligible need
- Prevention duties – Prevent, reduce and delay needs

Joint NHS and solely NHS duties:

- Joint Adult Social Care and health duties to promote wellbeing
- NHS duty to cooperate with Local Authorities
- NHS responsibilities at hospital discharge
- Continued Healthcare (CHC) funding and assessments for breaks (NHS)
- Forthcoming publication on NHS legal responsibilities towards carers

Young carers and parent carers

- Adult Social Care have responsibilities to identify & support young carers
- Children Act 1989/Children and Families Act 2014 - Duties upon the local authority to carry out both young carers needs assessments and young carers transition assessments before the young carer turns 18 years old and when it would be of “significant benefit” to the individual.
- Parent carers – Parents of a disabled child have the same right to support as carers who look after an adult. There is a duty on councils to offer a carer’s assessment to any parent of a disabled child under the age of 18.

As an employer: Equality Act 2010

- Right to request flexible working
- Right to emergency time off for dependents

Overarching

- Equality Act 2010 – Employers and providers of goods and services must not treat carers less favourably than those without caring responsibilities.

- Human Rights Act
50. The Carers UK guide to getting help and support in England provides a comprehensive overview particularly relating to assessments:
<https://www.carersuk.org/images/Factsheets/Assessments - England factsheet April2019.pdf>

Key Relevant National Policy

NHS Long Term Plan

51. Published by NHS England in 2019, the NHS Long Term Plan places a strong emphasis on improving early intervention and support for patients and for carers. Within the plan there are key commitments relating to carers:
- Carers will benefit from greater recognition and support. We will improve how we identify unpaid carers and strengthen support for them to address their individual health needs. We will do this through introducing best-practice Quality Markers for primary care that highlight best practice in carer identification and support.
 - Continue to identify and support carers, particularly those from vulnerable communities.
 - Carers should not have to deal with emergencies on their own. We will ensure that more carers understand the out-of-hours options that are available to them and have appropriate back-up support in place for when they need it.
 - Young carers - The NHS will roll out 'top tips' for general practice which have been developed by young carers, which include access to preventive health and social prescribing, and timely referral to local support services.
 - We will ensure that initiatives around personalised care including personal health budgets and social prescribing are fully reflective of carers' needs.
 - Patients, clinicians and the carers working with them will have technology designed to help them. There will be a digital service for managing interactions with the NHS, ready access to personal records, care plans, expectations, appointments and medications, to enable care to be designed and delivered in the place that is most appropriate for them.

Carers Action Plan 2018-2020

52. This action plan outlines the cross-government programme of work to support carers in England and builds on the 2008 National Carers Strategy.

NICE guideline on Supporting Adult Carers

53. The National Institute for Health and Care Excellence (NICE) published the guideline in January 2020. This guideline covers support for adults (aged 18 and over) who provide unpaid care for anyone aged 16 or over with health or social care needs. It aims to improve the lives of carers by helping health and social care practitioners identify people who are caring for someone and give them the right information and support. It covers carers' assessments, practical, emotional and social support and training, and support for carers providing end of life care.

Key Southampton Policies

Southampton Strategy for Unpaid Carers and Young Carers 2016-2020

54. This joint strategy represents the first strategy in Southampton that sought to identify what is needed to improve the lives of carers now and in the future, and to change services to meet those needs.
55. The Strategy contained six key priorities to improve lives and support of Southampton's carers. Progress has been made against the priorities, but governance arrangements and accountability challenges have limited the effectiveness of the strategy in delivering the desired improvements to carers outcomes.
56. A new strategy for unpaid carers in Southampton is in development, running in parallel with this inquiry, that will seek to set out ambitions and priorities that are supported by clear and appropriate action plans.

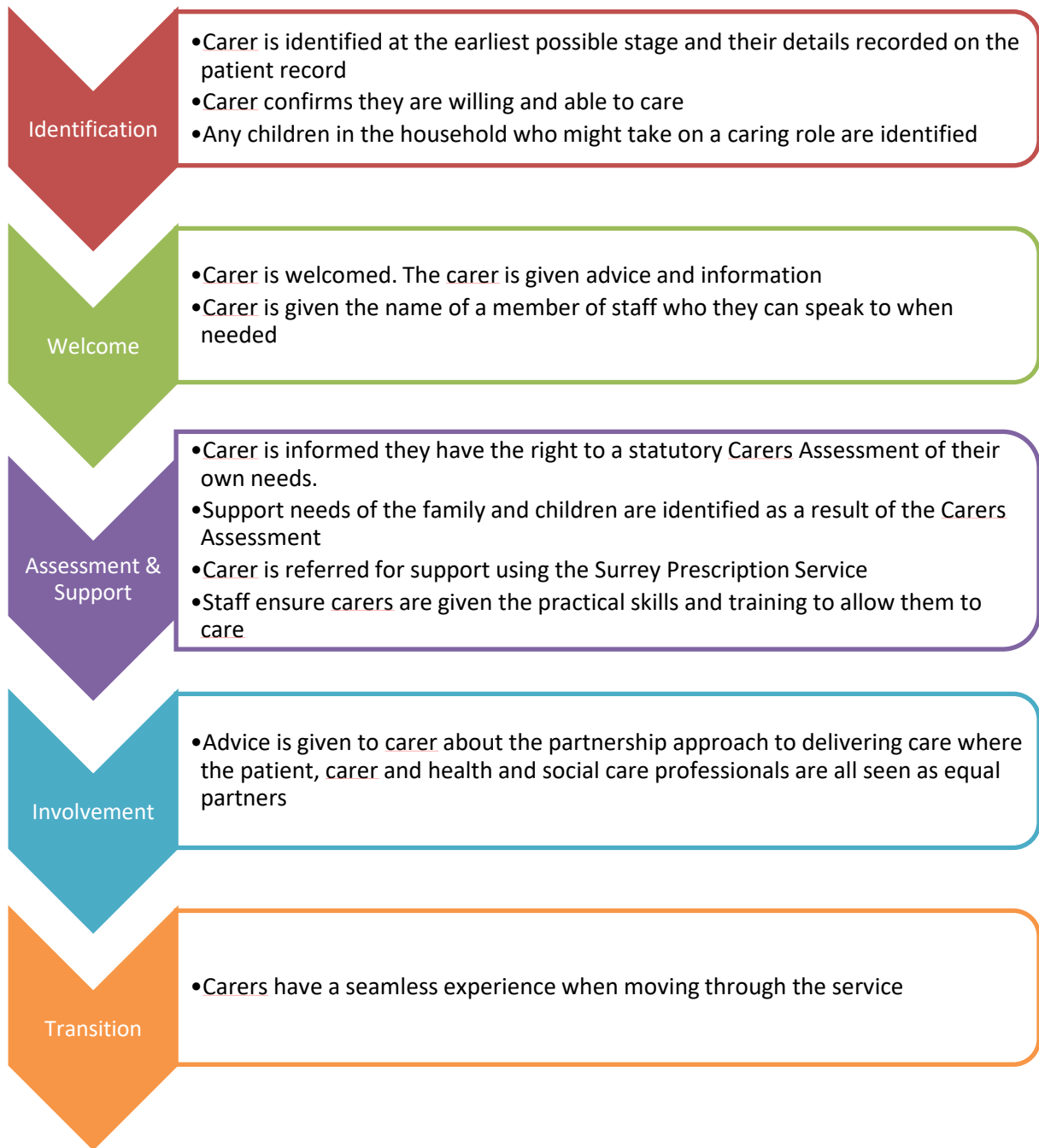
Southampton Health and Care Strategy 2020-2025

57. Health and Care partners across the city have worked together to co-produce and agree a shared vision and a place-based five year strategy to improve outcomes for the city's population.
58. Southampton's strategic plan is the City's contribution to the wider Hampshire and Isle of Wight five year response to the NHS Long Term Plan. At the heart of the strategy is the Better Care Southampton Programme, which has three main areas of focus, all of which impact on outcomes for carers:
 - Promoting independence and wellbeing
 - Timely and appropriate access to care and support
 - Proactively joining up care across health and social care, physical and mental health and primary and secondary care.
59. In addition, a number of other strategies and policies that aim to improve support for unpaid carers in Southampton have been developed or are in development. NHS providers in the city, including Solent NHS Trust, Southern Health NHS Foundation Trust and University Hospital Southampton Foundation Trust have Carer's Strategies/Plans, or are producing them to improve the support they are able to provide to carers.

Support for carers - What have carers identified as being important to them?

60. As quoted at the start of this report, The Carers Action Plan 2018-2020, reflecting carers feedback to Government, states that *'too often carers feel they are on their own, do not feel respected, valued and supported for the huge contribution they make. They feel that what they do is sometimes taken for granted and overlooked, which often takes a toll on their own wellbeing. Not only do carers face emotional challenges but they sometimes navigate through complex systems with little formal guidance and direction.'*
61. To address these concerns, whilst recognising that every carer is an individual, a number of organisations have worked with carers to outline some common goals shared by carers.
62. In the foreword to the Carers Action Plan 2018-2020, analysis of evidence submitted by carers, identified that carers need:
 - To be recognised and valued
 - Access to information and support to provide the best care they can
 - To be helped to balance their caring responsibilities with their own employment and to preserve their personal health and wellbeing.
63. Common goals presented to the Inquiry Panel by Emily Holzhausen OBE, Director of Policy at Carers UK included the following:
 - Identified, but not “outed”
 - Valued, including knowledge and opinion
 - Involved
 - Feeling in control
 - Being knowledgeable
 - Being linked to friends/society (not lonely)
 - Being able to continue working/return to work
 - Time to yourself and a life outside of caring
 - Positive health and wellbeing
 - Services and support that fit around people
 - Equality and society respect
64. Reflecting the common goals identified, to help ensure that carers receive the type of support they need at the right time, Surrey has produced a Carers Pathway. The five step pathway has been co-produced with carers and has been adopted by local NHS organisations and Surrey County Council.
65. The Surrey Carers Pathway has been designed to serve two purposes: to fit within existing pathways familiar to community health care and hospital staff; and to help health care staff identify, recognise and support carers.

Figure 1 – Surrey Carers Pathway



66. Surrey is recognised as a best practice provider in how it supports carers. This bespoke Surrey specific carers pathway, can, by using the key steps – **Identification; welcome; assessment and support; involvement and transition** be used as a template to compare the support carers receive in Southampton with good practice identified during the inquiry, and the support needs identified by carers.

Assistance for carers – What is the position in Southampton?

67. Using the Surrey Carers Pathway as a guide, this section will, utilising the evidence presented to the Inquiry Panel, seek to identify against each key step how Southampton is performing, outline initiatives and developments in Southampton that can help improve outcomes for carers, and provide examples of best practice.

Key Step 1 - Identification

- Carer is identified at the earliest possible stage and their details recorded on the patient's record
- Carer confirms they are willing and able to care
- Any children in the household who might take on a caring role are identified

68. It is a requirement of the Care Act 2014 for local authorities to have due regard to the importance of identifying carers who may have support needs and explain the advice and support available to them.
69. The 2020 NICE guideline on Supporting Adult Carers recognises a key barrier to the provision of appropriate support to carers is that they are often not identified. Many carers do not think of themselves as carers or are not identified by health and social care practitioners as such (so called 'hidden carers') and do not know about the support available.
70. Despite the introduction of legislation, the NICE guideline states that *'it is still the case that only a small proportion (in one area estimated as 7%) are identified as unpaid carers by social care and health organisations, so many are missing out on help and support.'*
71. In the introduction to this report it was reported that the number of carers living in Southampton, including over 2,000 young carers, is estimated to be about 32,000. As of October 2020, Carers In Southampton, the provider of a support service for adult carers in the city, were aware of 4,068 carers, and No Limits, the commissioned provider of support for young carers in Southampton, were aware of 420 young carers. This is a total of 4,488 carers identified by the directly commissioned carer support organisations. This equates to roughly 14% of the estimated carer population in Southampton.
72. It is likely that a number of carers have been identified and registered by primary care and other NHS providers in the city but are not known to Carers In Southampton or No Limits. The number of carers registered with GP Surgeries in Southampton in January 2021 was 5,104 which is 1.8% of the total number of 290,242 patients recorded.

Feedback on the identification of carers in Southampton

73. Dr Karen Malone, GP at Old Fire Station Surgery in Woolston, provided a primary care perspective on the identification of carers. Reflecting the pressure on GPs the following comments about carer identification were made:

- *'Much of the identification of carers is ad-hoc'*
 - *'Doctors do not always know carers, carers may have to identify themselves'*
 - *'Need to get better at carer identification, especially parents that are carers for children with additional needs, carers of people with mental health conditions and young carers'*
 - *'Primary Care is more than just GPs. All staff in a surgery can help to identify carers and update the records.'*
74. Feedback related to carer identification has also been provided from carers through the carer support organisations in Southampton.
- *'On the identification point. Our GP surgery won't recognise me as a carer because he's under 18!'*
 - *'Took a while to realise I was a carer'*
 - *'I look after my mum and didn't see myself as a carer just a daughter ... a GP referred to me as an unpaid carer'*
 - *'Admiral Nurse pointed out that I was a 24 hour unpaid, but voluntary carer.'*

Developments in Southampton to improve the identification of carers

75. At meetings of the Inquiry Panel, information relating to initiatives in train, or planned for Southampton, that could help to increase the awareness and identification of carers was discussed. A number of these initiatives have been outlined below.

Awareness raising - COVID-19 Vaccinations

76. Whilst the pandemic, and associated lockdowns, has been extremely challenging for carers, the vaccination programme, and the identification of carers as a priority group, has resulted in an increased profile of carers in Southampton.
77. Carers already registered with their GPs or who are in receipt of a carers benefit were automatically invited for the vaccine. Following an awareness campaign, carers who were unsure whether they were registered as a carer with their GP or are not receiving Carers Allowance were encouraged to complete a form with Carers In Southampton who then notified the NHS that they were a carer. This has resulted in an additional 800 carers being identified in Southampton.

NHS Provider Initiatives

78. University Hospital Southampton (UHS) - Established a Patients Hub during the lockdown to help manage access to the hospital. The Hub is a single point of access for patients and carers, helping to signpost support.
79. A carers programme is run by the Patients Hub and a Carers Support Lead has been recruited. To help identify and register carers UHS launched a Carers Card to be used in conjunction with the National Sunflower Lanyard.

80. As of 26 November 2020, 250 Carers Cards had been dispensed by UHS. Signing up to the card enables carers to be recorded on the Patient Administration System as carers.
81. By identifying and flagging carers UHS are now in a position to be more flexible in offering outpatient appointments that meets the requirements of the patient's carer. This information can be sent to the patients GP practice.
82. Southern Health - As part of an extensive support service for carers, Southern Health is working towards accreditation for the Triangle of Care initiative. 'Triangle of Care' is a national initiative launched by the Carers Trust. This initiative promotes the importance of involving carers, alongside service users and staff. Southern Health is working hard to embed the Triangle of Care standards within its work.
83. Part of this initiative is being carer aware and identifying carers. So far in Southampton 176 members of staff have been trained in being carer aware and in engaging with carers, and 27 carers leads have been identified.
84. Solent NHS Trust - Has been working to increase the early identification of carers, particularly in Portsmouth through its work with the Portsmouth Carers Service. Solent NHS Trust recognises the value of early identification of carers in reducing barriers to health prevention activity and is improving identification and support for carers working for Solent NHS Trust.

Identification of carers – What does good look like?

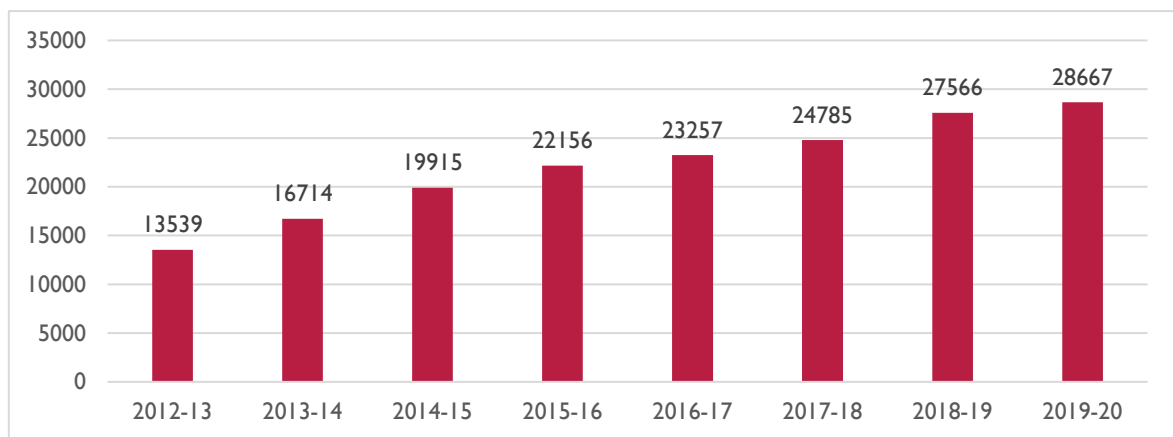
85. Amongst a number of recommendations related to the identification of carers, the 2020 NICE guideline on Supporting Adult Carers⁹ recommends that health and social care practitioners should:
 - Actively seek to identify carers (in line with the requirements of the Care Act 2014)
 - Use every opportunity to identify carers, including GP appointments, flu jab appointments, home visits, outpatient appointments, social care and other needs assessments, including admission and discharge assessments and planning meetings. Record details about carers identified (with the carer's consent).
 - Encourage carers to recognise their caring role and seek support, explaining the benefits for both them and the person they care for.
86. The NICE guideline on Supporting Adult Carers recommends that health and social care organisations should, amongst other things:
 - Encourage people to recognise their role and rights as carers
 - Ensure their policies and systems encourage the identification of carers, including by developing formal processes to help them do so.
 - Ensure that all staff likely to come into contact with carers understand their responsibilities under the Care Act 2014 in relation to identifying carers.

⁹NICE guideline – Supporting Adult Carers (Jan 2020) <https://www.nice.org.uk/guidance/ng150>

Surrey's approach to identifying carers

87. Surrey recognises that identifying carers is the first step to providing them with the support they need to maintain their own mental and physical health and wellbeing. In her presentation to the Panel, Debbie Hustings, Partnership Manager (Carers) at Surrey Heartlands Integrated Care System, outlined, as part of a wider co-ordinated and integrated approach to identifying and supporting carers, the approach being used to increase the identification of carers by health professionals.
88. The NHS is key in identifying carers. 70% of carers come into contact with health professionals yet health professionals only identify one in ten carers. More specifically, GPs are reported as only identifying 7%.¹⁰
89. The Surrey Carers Team has been collecting data on the number of carers registered within GP practices since 2008. There is now a Surrey Carers Key Performance Indicator for primary care that was launched in July 2019, this is monitored through an annual survey.
90. The number of carers registered with Surrey GPs has increased every year and at the end of 2019/20 28,667 people, approximately 20% of the adult caring population in Surrey, now have their caring role recorded with their GP. Entering a patients caring role onto their record reduces the need to repeat their story to health professionals.

Figure 2 – Surrey GP Carer Registration Year on Year



91. In Surrey 90% of GP Practices are signed up to the GP Carer Quality Markers initiative outlined in the NHS England Long Term. This scheme is designed to identify best practice in carer identification and support within primary care. Surrey have promoted the new GP Carer Quality Markers across their system and 76 practices have completed a full assessment. As of November 2020, no GP practice in Southampton had a GP Carer Quality Marker.
92. The NHS is a major employer. An important element of the approach in Surrey is to identify and support carers working within NHS organisations. A Surrey Carers

¹⁰ <http://www.england.nhs.uk/wp-content/uploads/2014/05/commitment-to-carers-may14.pdf>

Workforce Task Group has been established and is helping to increase the identification of carers.

Young Carers in School Programme – The Children’s Society & Carers Trust

93. In a survey published by The Children’s Society, 39% of young carers said nobody in their school was even aware of their caring responsibilities.¹¹
94. Jointly run by the Carers Trust and The Children’s Society, the Young Carers in Schools programme is an England-wide initiative that equips schools to increase identification of, and improve outcomes for, young carers in schools. It also awards good practice with a Young Carers in School Award.
95. This programme has been designed with young carers, teachers and school staff and it includes free resources such as a Step-by-step Guide for Leaders, Teachers and Non-teaching Staff.
96. Information presented to the Inquiry Panel identified that schools who have achieved their young carers in school award have found increased levels of identification of young carers within their school¹² and the following impacts:
 - 73% of schools reported young carers’ classroom engagement had improved
 - 63% reported improvements in young carers’ achievement
 - 83% of young carers demonstrated increased happiness; 94% of schools reported to have a better understanding of the support required for young carers.
97. In Southampton, No Limits does not have capacity in the current young carers team to enable the roll out of the Young Carers in Schools programme in Southampton. At present no schools in Southampton are accredited with the Young Carers in School Award.

The Young Carers Package - Scotland

98. In Scotland, Young Scot (the organisation behind the free national entitlement card for 11-26 year olds in Scotland), has worked with a group of young carers to develop a package of tailored entitlements and rewards, such as sports and leisure activities specifically for young carers. The Young Scots Package works alongside the Young Scot entitlement card.¹³
99. Discount cards are frequently used to encourage carers to identify themselves. In Southampton all eligible carers, including adult carers, parent carers and young carers are entitled to a Carers Card which provides access to discounts for goods and services in and around Southampton.
<https://www.carersinsouthampton.co.uk/carers-cards>
100. No Limits, the organisation that provides the Southampton Young Carers Project, is responsible for carrying out eligibility assessments for the carers card for young carers. During the inquiry young carers who gave evidence identified that a specific Young Carers Card, that had discounts that were matched to the interests

¹¹ <https://www.childrenssociety.org.uk/what-we-do/our-work/supporting-young-carers/facts-about-young-carers>

¹² <https://www.childrenssociety.org.uk/sites/default/files/2020-10/young-carers-and-school.pdf>

¹³ <https://young.scot/campaigns/national/young-carers>

and needs of young carers, such as transport and days out, would help to raise awareness of young carers, and could help increase the number of young carers registered as carers and in contact with services.

Portsmouth Carers Centre – Community Hub

101. Portsmouth Carers Service is based within Portsmouth Carers Centre. It is a community hub for a range of carer activity groups, including training, cooking, activities and events.
102. As a high profile community hub it helps to raise awareness of carers and encourages carers to self-identify as carers or be referred by family or friends.
103. Carers In Southampton is based in Meon House, a building at the rear of 189 Portswood Road. It is not visible from the road and its location, profile and facilities does not lead it to becoming a community hub for carers. Given the impact of the pandemic on city centre real estate it may be the ideal time to identify a community hub/venue which makes it easier for carers to access support when needed.

Recommendations to increase the identification of carers in Southampton

104. Identifying carers is essential. As noted by Surrey, identifying carers is the first step to providing them with the support they need to maintain their own mental and physical health and wellbeing.
105. Evidence presented to the Inquiry Panel has revealed the scale of the problem in Southampton with the vast majority of carers not being known to health and care providers or the direct providers of support to carers in the city.
106. To help to address this challenge the following actions are recommended:

1. Encourage and support primary care providers in Southampton to become more carer aware by adopting the GP Carer Quality Marker.
2. Akin to the Surrey Carers Workforce Task Group, to lead by example, promote the identification and support for carers employed within the City Council and NHS providers operating in Southampton.
3. Promote the Young Carers in Schools Programme within Southampton's schools and empower schools to identify and support young carers.
4. In conjunction with young carers, establish a Southampton Young Carers Identification Card and seek the support of appropriate organisations to offer discounts to our young carers.
5. Support the identification of a community hub/venue which makes it easier for carers to access support when needed.

Key Step 2 – Welcome

- Carer is welcomed. The carer is given advice and information
- Carer is given the name of a member of staff who they can speak to when needed

107. Access to good information, advice and guidance at the right time, and in the right format, can have a significant impact on a carers quality of life, the control they have over their lives, and can prevent problems from escalating.
108. Under the Care Act 2014, local authorities must establish and maintain a service for providing people with information and advice relating to support for carers. However, many carers are unaware that any advice and services are available to them, or they may not have time to search for them.¹⁴
109. Emily Holzhausen OBE, Director of Policy at Carers UK, explained to the Panel that chasing information is exhausting for carers but that providing good information, advice and guidance to carers is not an easy task. This is due to the following factors:
- The constantly changing population of carers (1/3 turnover annually)
 - Carers are on different stages on the caring journey – knowledge levels differ
 - Carers capacity and ability to take on board information
 - The range of channels where people find information
 - How people consume information
 - Workers – i.e. those juggling work and care
 - The diversity of the carer population.
110. In Southampton information, advice and guidance for carers is provided by a number of organisations and is available in a number of formats. No Limits offer information advice and guidance to young carers and Carers In Southampton offer signposting and information, including a newsletter for adult carers.
111. Southampton City Council provides information to carers on its Southampton Information Directory and NHS providers have carers webpages with timely information and guidance.
112. Information for carers is also provided by a number of indirect providers of support for carers, such as Alzheimer’s Society, who provide advice to carers as part of their role to support people with a specific disability, medical condition or illness.
113. In Southampton a consortium of 6 organisations (Citizens Advice Southampton, Age UK Southampton, Rose Road Association, EU CLEAR, No Limits and The Environment Centre (close working exists with SARC)) – Called Advice in Southampton provide information, advice and guidance in the city.

¹⁴ NICE guideline – Supporting Adult Carers (Jan 2020) <https://www.nice.org.uk/guidance/ng150> -p36

114. Services are quality assessed to ensure they meet the advice quality standard mark. The contract operates on the no wrong door for advice principle. A service user will be referred, with consent, via Refernet to the most appropriate provider with all relevant details to reduce the need for the client to repeat the information.
115. In Southampton 'The Zone' distribution list of approximately 300 local partners enables information on initiatives and challenges to be shared quickly with key stakeholders across the city. This is recognised as best practice
116. Carers benefit from specialist welfare benefit advice from Citizens Advice Southampton and can access specialist advice from MacMillan Cancer Support and MS Society. Barriers to support carers exist, carer identification remains low and carers may be confused as to which agency can help them but Advice in Southampton is working with Carers in Southampton to improve understanding of these barriers.

Feedback on the advice and information for carers in Southampton

117. Selected feedback from carers, sent via Carers In Southampton includes the following:
 - *'There is no lack of information but a definite lack of structure....I find that there is sometimes too much information online and finding the right contact at a local level can be time consuming.'*
 - *'Carers in Southampton have supported me by talking things through and advising on small financial support. They have been very helpful'*
 - *'Information from Carers UK on planning quick and simple meals was very helpful, joined the organisations Facebook pages was helpful'*
 - *'Yes good help and advice receiving when needed'*
 - *'Through my doctor's surgery, I found out about Carers In Southampton. Before that, some help from SARC, but most help I've found by doing my own homework.'*

Developments in Southampton to improve the advice & information for carers

118. At meetings of the Inquiry Panel, information relating to initiatives in train, or planned for Southampton, that could help to improve the information, advice and guidance provided to carers was considered. A number of these initiatives have been outlined below.

Improving the Southampton Information Directory (SID)

119. Southampton Local Information Directory (SID), the City Council's online offer, is not performing the role it is designed to do at present. This has resulted in other platforms trying to fill the gap, resulting in a plethora of information sources.
120. Carers information is currently incorporated into wider Adult Social Care information in the SID, but the SID is separate from information on the Council's website on Adult Social Care.
121. Southampton City Council are now developing the SID and website following the principles of no wrong door and many routes to information.

122. The platform is being built around customer journeys, following life events. Becoming a carer (wording subject to consultation) is to be one of the life events used. The platform will use cookies ('if you like this then you may be interested in this') and should also be a resource for Council employees to improve the consistency of advice given.
123. Proposals are that the best available advice and information from national and local sources will be on the SID and that it will be structured to avoid users getting lost. It is recognised that there needs to be an easy way to update the information.
124. When the information was presented to the Panel the SID was in the discovery and design phase. The Council have been keen to engage with service users and providers in the development and design of the content.

Digital Strategy

125. The City Council is developing a Digital Strategy. A priority will be to work with partners on skills, access and inclusion. This development is relevant as 600 carers known to Carers in Southampton are not online.

Department for Work and Pensions (DWP) / Southampton City Council Youth Hub

126. A Youth Hub has been established in Southampton as a result of a DWP and Southampton City Council initiative. The Youth Hub team will signpost to advice and support around housing, benefits, health and wellbeing to provide a holistic and person-centred service for young people, including young carers. It will utilise a wealth of virtual tools including web chat, video conferencing, online resources and podcasts.

Expansion of Refernet Providers

127. Refernet, the system employed to share information between Southampton advice agencies, is being opened up to a greater number of providers in the city. The more agencies on board the better the journey will be for the carer. Talks are ongoing with Carers In Southampton to enable them to access Refernet.

Partnership with the British Legion

128. Through the Armed Forces Community Covenant the City Council / Integrated Commissioning Unit and Carers In Southampton are working with the British Legion on a referral process that will link eligible carers to the information, advice, guidance and funding available from the British Legion.

Social Prescribers and Community Navigators

129. One of the top 5 priorities in the NHS Long Term Plan is that people will get more control over their own health and care when they need it. This is referred to as Personalised Care.
130. One of the 6 components of Personalised Care is connecting people to help and support in the community through social prescribing. A service that bridges information and support, carers should have access to social prescribing in all areas of England through referral to a social prescribing Link Worker from primary care and other agencies such as local authority social care teams. This includes both adult carers and young carers.

131. Social Prescribing Link workers should understand what a carer is, the challenges they may face with managing their health and wellbeing, and understand what services exist in their local area that cater explicitly to carers, alongside wider services, groups and activities that may be of benefit.
132. In Southampton Primary Care Networks have started employing social prescribers to work in primary care settings, these are in addition to community navigators employed by the SO:Linked service and a social prescribing service for children and young people, which is accessible to Young Carers, provided by No Limits.
133. SO:Linked is a city wide service which offers a social prescribing/navigation overview and joined up approach which means it can work effectively on city wide programmes like Dementia Friendly Southampton.
134. Southampton is ahead of most areas in delivering this service. The social prescribers and community navigators are working closely together, including accessing So:Linked training sessions. Carers have been proactively identified as a group that may benefit from social prescribing approaches, and, collectively they will help to link carers to the support, activities, information and guidance available in Southampton, thereby saving carers valuable time and effort.

Advice and Information – What does good look like?

135. The NICE Guideline Supporting Adult Carers, published in January 2020, recommends that:
 - Local authorities should provide information to carers to support them in their caring role. Information provision must meet the requirements of the Care Act 2014.
 - Practitioners in health and social care should use every opportunity to tell carers they have a right to information and support and how to get it.
136. The NICE guidance identifies that Information for carers should be up to date and cover:
 - The range of support and advice recommended in the NICE guidelines
 - How to access social and community support for carers
 - Useful further sources of information and support such as carer groups and forums.
137. Emily Holzhausen OBE, Director of Policy at Carers UK identified a number of 'must haves' for the delivery of good information, advice and guidance for carers. The list was as follows:
 - Very good awareness of carers by all frontline staff – are they Carer Aware?
 - Peer support is important as well as professionals who are experts
 - Take the best from good strong local provision and what is appropriate nationally e.g. gov.uk, nhs.uk, carersuk.org, ageuk.org.uk, Mencap.org.uk, contact.org.uk

- Essential local mapping and good understanding of user journey: signposting, referrals, in-depth advice, advocacy.
138. In response to the above, in Southampton carer awareness training is provided to care professionals via an e-learning course¹⁵. The Panel were also made aware of carer awareness sessions provided by Hampshire Carers Together for Southern Health staff.
139. Peer support is available for some carer groups. The Panel were informed about Re:Minds, a parent led support group for parents with children with mental health issues. The Panel are aware that the Parent Carer Forum and the Southampton Autism Support Service offer peer support and online peer support forums, such as Time for Talk (Alzheimer's Society) and the Carers Forum (Carers UK,) are also available.
140. Proposals for the Southampton Information Directory (SID) redesign include utilising the best local and national information and is being designed around the carers journey.

Recommendations to improve the provision of advice and information to carers in Southampton

141. Providing information is a statutory requirement and giving carers the right information and advice at the right time can help carers continue caring, while managing other aspects of their lives. Research by Carers UK shows that costs incurred are outweighed by the benefits of helping to avoid crisis situations such as unplanned hospital admissions and carer health problems.
142. With strong foundations and encouraging developments planned, carers in Southampton should have access to good information, advice and guidance. To help carers and social prescribers / community navigators the following is recommended:

1. Develop formal processes to encourage regular communication between the providers of carers information, advice and guidance in Southampton. Thereby duplication is minimised, advice is consistent, the no wrong door approach is applied and carers, or advocates, can navigate the system easily.

¹⁵ http://www.southampton.gov.uk/elearning/carers-aware/story_html5.html

Due to the range of issues to be considered the Assessment and Support Key Stage in the Surrey Pathway has been separated into Assessment & Support elements.

Key Step 3a) – Assessment

- Carer is informed they have the right to a statutory Carers Assessment of their own needs.
- Support needs of the family and children are identified as a result of the Carers Assessment

143. Many carers find it easier to continue in their caring role if they can get some support. Local councils must provide or commission care and support for people who require care, and their carers. The way they decide what support is needed is by carrying out assessments.
144. All carers are eligible for an assessment but it should be proportional to the needs of the carers so could range from a short conversation and advice / signposting given, to a written assessment followed with a support plan to meet the needs of the carer.
145. Only carers who meet an eligibility threshold are entitled to receive support that is beyond the support available to every carer.
146. Some key principles of all types of assessments are that they:
- should be offered on the appearance of need or when requested by a carer
 - can be combined with the person being cared for, and/or any other carer so that the impact of the combined needs are taken into account in the individual's assessment. Combined assessments can be done at the same time or separately and by the same assessor or different assessors
 - are undertaken in whole family approach way to assessments, particularly when assessing young carers. This means considering how the needs of the person being cared for impacts on other family members or anyone in their support network
 - can be carried out jointly with another agency, such as the NHS, to ensure that all the professionals involved in a person's care are talking to each other when decisions about care are being made.
147. There are a number of different assessments for carers, depending on the type of carer they are. Below is a summary of the various assessments paraphrased from the Carers UK factsheet - Assessments and the Care Act.¹⁶

Carers Assessment

148. A carer's assessment is for adult carers of adults (over 18 years) who are disabled, ill or elderly. It is an opportunity to discuss with your local council what support or services you need. The assessment will look at how caring affects your

¹⁶ [https://www.carersuk.org/images/Factsheets/Assessments - England factsheet April2019.pdf](https://www.carersuk.org/images/Factsheets/Assessments_-_England_factsheet_April2019.pdf)

life, including for example, physical, mental and emotional needs, and whether you are able or willing to carry on caring. Carers assessments evaluate needs and eligibility for support and services.

149. If you are sharing caring responsibilities with another person, or more than one person, including a child under 18, you can each have a carer's assessment. A carer under 18 who is sharing a caring role would receive a young carers assessment.
150. You should be offered an assessment by the local council adult social services department of the person you are looking after, or the organisation they commission to do assessments. Your assessment should cover:
 - your caring role and how it affects your life and wellbeing
 - your health and wellbeing – physical, mental and emotional issues
 - your feelings and choices about caring
 - work, study, training, leisure
 - relationships, social activities and your goals
 - housing
 - planning for emergencies.

Parent Carers Needs Assessment

151. The Children and Families Act 2014 amends the Children Act 1989 requiring local councils to assess parent carers on the appearance of need or where an assessment is requested by the parent. This is called a parent carers needs assessment. This assessment can be combined with one for the disabled child and could be carried out by the same person at the same time.
152. A parent carers assessment must cover all the points listed in a carers assessment but also has two important additional considerations:
 - whether it is appropriate for the parent to provide, or continue to provide, care for the disabled child, in the light of the parent's needs for support, other needs and wishes.
 - the need to safeguard and promote the welfare of the child cared for, and any other child for whom the parent carer has parental responsibility.

Young Carers Assessment

153. Young carers rights to be assessed come mostly from the Children's Act 1989 and the Children and Families Act 2014 but they are also enshrined in the Care Act 2014, particularly transitional assessments.
154. As part of the whole family approach, if there is a disabled adult being cared for, then the local council has a duty to consider whether there are any children involved in providing that care, and if so, what the impact is on that child.
155. The local council must involve the child with caring responsibilities, their parents and any other person the young carer requests in the assessment process. The assessment itself must look at whether or not the young carer wishes to continue

caring, and whether it is appropriate for them to continue caring. When doing this they have to take into account any education, training, work or recreational activities the young carer is or wishes to participate in.

156. Using the whole family approach may result in giving additional support to the person being cared for, or an adult carer, so that the young carer is not providing excessive or inappropriate care.

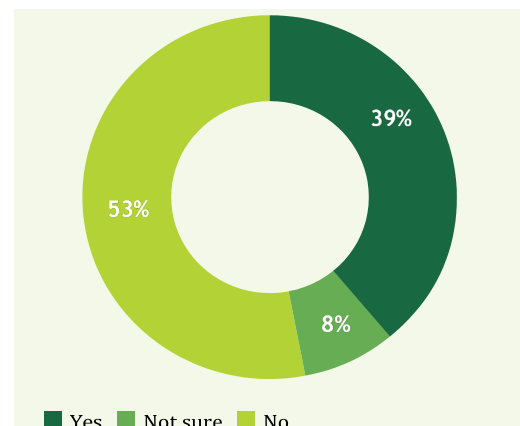
Transition Assessments

157. Local councils must provide support to enable individuals and families to plan ahead so that there are no gaps in services when a person becomes 18. An assessment helps identify services that may be required during the transition to adulthood.
158. The Care Act introduces a new duty on local councils to carry out assessments for the following individuals:
- Children receiving care and support who are approaching their 18th birthday. This is called a Child’s Needs Assessments (CNA) ‘in transition’.
 - Carers of disabled children who are approaching their 18th birthday. This is called a Child’s Carer’s Assessment (CCA) ‘in transition’.
 - Young carers who are approaching their 18th birthday – this is called a Young Carer’s assessment (YCA) ‘in transition’.
159. A transition assessment must be offered if there is ‘significant benefit’ to the child or adult / young carer if an assessment is made and where:
- a young carer may require support in their caring role beyond the age of 18 i.e. if they intend to carry on caring and become a young adult carer; or
 - a disabled child or carer of a disabled child is likely to have care and/or support needs after the child becomes 18.

Does everybody receive an assessment?

160. There are no definitive figures identifying how many carers receive an assessment of their needs.
161. An online survey in November 2019 of carers of people living with dementia in England and Wales revealed that only 39% of carers had received a carers assessment.
162. For the 53% who had not had an assessment this was due to not having been offered one (47%), other reasons (22%), such as not knowing / complications with the process or not being the main carer. 16% reported not being aware of carer assessments, while 4% reported having been told they were not eligible for one.

Fig 3: Have you had a carers assessment?



Source: The Fog of Support – Alzheimer’s Society

163. Some of those carers who indicated that they had received an assessment highlighted the length of time waiting for an assessment.
164. The survey, published by Alzheimer's Society, also reported feedback that the standard of carers assessments is variable with 3 prominent themes raised:
- Impersonal and conducted by telephone
 - Limited in the understanding of individual circumstances
 - Challenges in knowing what to ask in terms of support.¹⁷

Assessments in Southampton

165. In Southampton, through delegated powers conveyed in the Care Act and Children and Families Act, Carers In Southampton provide Carer Assessments and No Limits undertake Young Carers Assessments. Carers seeking Parent Carer Assessments are signposted to Southampton City Council's 0-25 service within Children's Services.
166. Both Carers In Southampton and No Limits receive referrals from statutory services. Referral by external agencies accounts for 25% of referrals to Carers In Southampton, including the City Council and NHS organisations.
167. The number of assessments undertaken for carers in Southampton is rising but remains low when considering the number of carers in the city. Information presented to the Health Scrutiny Panel in December 2020 stated that there were 243 in 2018/19 and 730 in 2019/20. The Panel were informed that No Limits received 126 referrals to the Young Carers Project in 2019/20.
168. Carers In Southampton assessments are undertaken by telephone and take approximately 45 minutes. Due to Covid, at the October 2020 meeting, members were informed that there was a 10 week wait for a Carers Assessment. Carer Assessments are uploaded to the Adult Social Care computer system.
169. The Young Carers Assessment takes approximately 45 minutes to complete, with the Early Help Assessments taking 60-90 minutes to complete. The waiting time for assessment is approximately 3-4 months.

Feedback on assessments for carers in Southampton

170. The most concerning feedback came from the Co-ordinator of Southampton Parent-Carer Forum, Vickey Kowal. In her presentation, when identifying the current difficulties being faced by parent carers, she stated that:
- 'Only a small percentage of parents are able to access a parent carers assessment (a statutory requirement). Those that do access one aren't involved in their own assessment.'*
171. Further comments related to parent carers assessments reinforced this point:
- 'Because my son comes under the jigsaw team, he gets a yearly assessment and my carer's assessment is included in that. So, I did not actually get asked any questions at all... nothing. My social worker is aware that, you know, obviously what his level of need. She knows that my daughter was being assessed for autism and they are aware that my mum has health needs as well. But she did not*

¹⁷ Survey published in The Fog of Support – Alzheimer's Society, 2020

ask me a single question about my perception of my caring role, what would help me in my caring role. She did not ask anything at all...in fact, I only know that a Parent Carers Assessment was carried out through my role with the carer forum.'

172. No Limits referenced that young carers considered their assessments to be 'time consuming' and some recorded comments from adult carers included:

- *'I know COVID has made everything very difficult but think assessments should, where possible, be face to face.'*
- *'Once I got in touch with Carers in Southampton. The process is lengthy - the waiting times to even have an assessment.'*

Developments in Southampton to improve the assessments

173. At meetings of the Inquiry Panel, information relating to initiatives in train, or planned for Southampton, that could help to improve assessments was considered. A number of these initiatives have been outlined below.

Special Educational Needs and Disability Services (SEND)

174. The Council is reviewing how other local authorities carry out parent carer assessments for those who are not open to, or eligible for statutory social care involvement. Parents will be central to the development of this process, and in the process itself.

Assessments – What does good look like?

175. The NICE Guideline Supporting Adult Carers, published in January 2020, recommends that:

- Local authorities, and social care organisations delegated by local authorities to carry out carers' assessments, should make arrangements for and carry out assessments in cooperation with other relevant health and social care organisations.
- Practitioners from health and social care carrying out or contributing to carers' assessments should work together to ensure that:
 - a) the assessment covers all relevant aspects of health, wellbeing and social care needs and
 - b) details of the assessment are shared with other practitioners and organisations who are involved in the assessment
- Health and social care organisations should ensure that practitioners who carry out or contribute to carers' assessments have training and skills in that role and access to specialist advice.
- The assessment should be jointly produced with the carer and reflect what matters most to the carer and what might help them achieve this.

176. Young Carers Assessments are supported with guidance from ADASS, ADCS, Children's Society and Carers Trust and recommend that adult and children services develop a Memorandum of Understanding to describe how they will work together when assessing both young and adult carers and the people in their care.

177. Local authority adult and children's services may have overlapping responsibilities in arranging to assess and, if appropriate, support young carers and the person

they care for. The primary responsibility for responding to the needs of a young carer rests with the service responsible for assessing the person they support, rather than depending on the age of the carer. This means that:

- young carers of disabled children are, the responsibility of children's services; whilst
- it will usually be the responsibility of adult services to identify whether children in the household/ family network are expected to assume inappropriate or excessive caring responsibilities for parental figures, or other adults.

Portsmouth Carers Service – Approach to assessment

178. In 2017/18 Portsmouth radically redesigned the assessment and support planning process for adult carers based on what carers wanted. Carers assessments now:
- Start at first contact, are proportionate and scalable
 - Barriers removed – no forms, open conversation in a way that suits the carer
 - Whole family approach where wanted, combined or joint assessments – work in progress
 - Focus on what matters - regularly includes health and wellbeing.
179. Portsmouth's assessment and support planning model currently meets the Key Features of Personalised Care and Support Planning as set out by NHS England. This will be discussed in greater detail in the next section.

Recommendations to improve assessments for carers in Southampton

180. Assessments are an integral part on the carers pathway to appropriate support. Given the estimated population of carers in Southampton too few assessments are being undertaken in the city. Assessments for carers should be proactively offered to people rather than wait for a request for an assessment.
181. Evidence presented to the Inquiry Panel has revealed some concerns about the assessment process and compliance with statutory requirements. This is particularly relevant to parent-carer assessments where feedback identified the difficulty getting a parent-carer assessment in Southampton.
182. The Panel also were informed about a different approach to assessments being employed in Portsmouth that has removed some of the barriers to assessments and is designed around the strengths of the carer and what matters to them.
183. To help address the challenges identified the following actions are recommended:

1. Review the process for undertaking parent-carer assessments to ensure that all parent-carers who have an appearance of need, or request one, have access to the statutory assessment, and, that they are actively involved in the assessment.
2. Incorporate the principles being applied in Portsmouth to the assessments being undertaken by carer organisations in Southampton.

Key Step 3b) – Support

- Carer is referred for support using the Surrey Prescription Service
- Staff ensure carers are given the practical skills and training to allow them to care

184. Fundamental to improving outcomes for carers is the provision of support that, if requested, helps a carer in their caring role and helps them to live a life outside of their caring role and achieve their own life goals.
185. Following the assessment carers should:
- Have access to a copy of their assessment
 - Be offered information and advice
 - Be told what support they are eligible for
 - Be told the arrangements for future reviews
186. If a carer is eligible for support local authorities have a legal obligation to meet these needs and must draw up a support plan detailing how these needs will be met.
187. In Southampton an eligible adult will receive a personal budget and will complete a support plan to decide how to spend it to meet their identified support needs in their assessment. Carers are given a direct payment so they can choose and buy the support themselves.
188. If the cared for person is supported by Adult Social Care it may be agreed that the best way to help a carer is by providing services directly to the carer, by providing services to the person the carer is looking after, or a combination of both.
189. The funding comes from Southampton City Council and it is not means tested. Carers will meet the eligibility criteria if there is (or is likely to be) a significant impact on a carers wellbeing as a result of their caring for another person.
190. There are three questions that the local council will need to consider when making their decision.
- Are your needs the result of you providing necessary care?
 - Does your caring role have an effect on you?
 - Is there, or is there likely to be, a significant impact on your wellbeing?
191. If you don't have eligible needs then you must be given a written decision explaining this. You must also be given advice and information about what could be done to prevent or reduce your needs either now or in the future. This advice and information should be based on your specific circumstances.

Support provided in Southampton

192. In Southampton, the number of adult carers receiving direct payments to pay for support to meet their needs, is rising each month. In November 2020 around 500 carers were in receipt of direct payments of between £17 and £42 per month.

193. The Panel were informed that direct payments are flexible and are currently funding carers to receive a range of services including gym membership, a massage, gardening service and domestic support.
194. In addition to direct payments, replacement care (care that replaces the care normally given by a regular carer) is also being provided through the provision of day care services, domiciliary care and overnight respite care (see table below). This enables some adult carers in Southampton to receive a break from their caring role.

Table 1 – Respite overnight breaks:

	Number of night provided per year 2019/20	Approximate number of Carers Supported
Kentish Road	499 days	Adults with Learning Disability
Way a Head	592 days	Adults with a learning Disability
Rose Road	473 days	Adults with a Learning/Physical Disability
Holcroft House	801 days	Dementia
Oak Lodge Nursing Home	398 days	Dementia
Other in 48 services	2613 days	
Total	5779 days	

195. At the October 2020 meeting the Panel were informed that No Limits were supporting 80 young carers in Southampton.
196. The range of support being provided to young carers through No Limits includes:
- Regular groups to provide the young people with knowledge, skills, respite, fun and soft outcomes sessions
 - Tailored workshops to the young people relating to their caring roles and their own needs - Not funded by the existing contract
 - 1:1 support for young carers with high levels of need in terms of their caring role
 - Matching young carers with volunteer befrienders to provide positive relationships, build self-esteem, confidence and engage with new activities in their local community
 - Providing fun activities and access to opportunities they might not otherwise be able to take part in - Not funded by the existing contract.
197. There are more young carers in the city than No Limits can provide an ongoing service for.

Feedback on support provided for carers in Southampton

198. Dr Karen Malone, GP at Old Fire Station Surgery in Woolston, stated that: *‘Seems to be little on offer with regards to respite or breaks.’*

199. Feedback received by young carers included the following positive comments:
- *'Young carers in Southampton is very fun and social because we get to have fun and meet other young carers'*
 - *'We do a lot of activities, which is fun. Young carers in Southampton helps me clear my mind when I am really stressed.'*
200. Feedback received by Carers In Southampton covered a range of issues, including the following that are representative of the responses provided by carers:
- *'Day care services & respite care through Rose Road. Very caring and competent staff, helpful. Our son loves going there, it gives us all a break'*
 - *'Respite care to give me a break'*
 - *'Genuine care that is easily accessed, that is of good quality, so I feel the person I care for is in warm, empathic, capable hands. Respite care.'*
 - *'To have some respite from the situation knowing that a good and trusted care cover person was in place'*
 - *'Support and respite that is not privately funded - even an hour per week'*
 - *'Cleaning, gardening, DIY'*
 - *'Have more of a social life'*
 - *'I am sure COVID-19 has scuppered most things but there has been a definite lack of support or training.'*
 - *'No training has been provided on how to be a carer.'*
 - *'To have more training for younger young carers. A lot of the opportunities/support are for 11+.'*
201. Gary Walker, Alzheimer's Society Service Manager, outlined a number of services that he thought were missing for carers in Southampton:
- *Respite Care; Continuity of care; Tailored care; Rapid Response; Priority access to services; Opportunities to talk to other carers; Advertising of existing support; Sitting service for medical appointments and transport.*

Developments in Southampton to improve the support for carers

202. At meetings of the Inquiry Panel, information relating to initiatives in train, or planned for Southampton, that could help to improve the support provided for carers was considered. A number of these initiatives have been outlined below.

Personalised Care – 3 Conversations

203. Adult Social Care and commissioners are aware that there is a need to increase access to support for carers and they understand the concerns carers have about replacement care and equitable access to replacement care.
204. There are a variety of ways in which you can provide the required support and replacement care to improve the carers physical and emotional wellbeing, enabling them to do something they want or need to do. In line with the NHS Long Term Plan priority of Personalised Care, Adult Social Care are looking to shift

towards a strength based and community asset based approach to supporting carers.

205. Adult Social Care have adopted ‘3 Conversations’ as an approach for assessment and care planning within Southampton. The conversations are suitable for adults and carers.

Figure 3 – 3 Conversations approach to assessment and care planning

Conversation	Needs assessment and care planning questions
1 - Initial contact	How can I connect you to things that will help you get on with your life – based on your assets, strengths and those of your family? What do you want to do?
2 – If people are at risk	What needs to change to make you safe and regain control? How can I help make that happen?
3 – If long-term support is needed	What is a fair personal budget and what are the sources of funding? What does good look like? How can I help you to use your resources to support your chosen life?

206. This personalised approach should lead to an agreed carers support plan that identifies the best solutions or actions to meet the desired outcomes.
207. The actions or solutions in the plan maybe different to what has traditionally been offered and should build on the carers own social networks and tap into what’s available in their neighbourhood to meet their needs.
208. It is recognised that, especially if improvements to identifying and assessing carers results in more carers being identified and assessed, a range of additional services will need to be commissioned to ensure that needs identified in the support plans are met and that carers are supported both in their caring role and to have a life outside of their caring role.

New role in primary care – Health & Wellbeing Coach / Care Co-ordinators

209. The use of social prescribers and community navigators to help connect carers to help and support in the community has been raised already in the report. To help build skills, knowledge and confidence, two further additional roles have been developed by the NHS for delivery in primary care that could be prioritised to support carers:
- **Health & Wellbeing Coach** - Can work with a carer to identify what’s important to them, set personal goals and appropriate steps, build skills and confidence to achieve goals, and use problem solving to work through challenges. They can support carers by working with them to develop their knowledge, confidence and skills to take control of their own health and wellbeing and to do more of the things in life that brings them joy.

- **Care Coordinator** - Can work with a carer to ease the potential burden of navigation and coordination across multiple health and care services. These roles will work with the carer to support them and may direct them to one of the recognised supported self-management interventions: health coaching, peer support and self-management education. In Southampton 2 out of the 6 Primary Care Networks are commencing recruitment of care co-ordinators.

Telecare Services

210. The Council’s Telecare service is an asset that can provide peace of mind to carers and has the potential to help people in their caring role. The service works in partnership with carers where possible and caters for a wide variety of needs. Southampton is fortunate to have a local responding capability. In most other areas the telecare service just links to a remote call centre. It is recognised that the service has great potential to help carers in their caring role.



Figure 4 - Telecare Sensors

Special Educational Needs and Disability Services (SEND)

211. Of particular relevance to parent carers, SEND services in the city are currently undergoing major transformation and SEND is one of the four workstreams of the Children’s Services Transformation Plan - Destination 22. As part of the reimagining of SEND, the SEND 0-25 Team and the Children’s With Disability Team (Jigsaw) have been amalgamated under one service lead in order that changes in the way we work spreads across all services that families access, and in order that families receive a more joined up service.
212. The children with disabilities service is currently viewed as a diagnostic led service. The Council are working with the national i-Thrive programme to move to a needs and family led model, so that access to services are determined on the presenting need and family context, in place of which label/diagnosis a child or young person might have.
213. Children’s Services are investing in support for parents at a targeted level, so that they can have access to workshops in areas such as autism and challenging behaviour. This will enable families to feel that they do not need to be in a specialist service to receive support.
214. Workforce development across mainstream and targeted services should mean that parents can receive support within their communities instead of being added to waiting lists.

City of Culture Bid

215. Southampton is bidding to become the UK City of Culture in 2025. This is a huge opportunity for the city to celebrate the wealth of cultural activity already taking place, showcase the city’s diversity and use these to address some of the challenges the city is facing. This could provide an opportunity to involve carers

and support them to experience the range of cultural activities the city offers giving them the chance to try new activities and meet new people.

Supporting carers – What does good look like?

216. The NICE Guideline Supporting Adult Carers states that '*Health and social care practitioners should regularly discuss with carers the value of having a break from their caring role and explain the options available*', and that '*Carers' breaks should:*
- *meet carers' needs for a break, for example in duration, timing, frequency and type of break*
 - *be arranged in a way that provides reliable and consistent support to the carer (such as avoiding last-minute changes that could lead to additional stress for the carer).*

Surrey's Prescription Service

217. Surrey has developed a sensible approach to providing carer's breaks and replacement care via the award winning Surrey Carers Prescription Service.
218. The service originally developed as a referral platform for GPs to refer carers for a Carers Break. GPs asked for alternative support options when their breaks money ran out. The menu was expanded to include all carers services commissioned.
219. Formally rolled out to all NHS Providers in Surrey since 2015 the service has, since inception dispensed 38,000 Carers Prescriptions.
220. All GP Practices in Surrey have signed up to the service and make referrals (The model can be delegated to a practice nurse).
221. The referral process is quick and easy to follow (a necessity stipulated by GPs) using GP Carer's Prescription Portal. The process and Carers Breaks Service are managed by Action for Carers Surrey.
222. Carer Breaks provide a one off payment to the carer of £300. Funding can be used on anything from golf, laptop or as contribution towards a holiday (83% choose this). The annual budget is £700k plus management fees.
223. Replacement Care is provided by Crossroads Care Surrey (CQC Outstanding provider). Up to 3.5 hours in house replacement care per week is available via a £1.8m contract (25,000 hours of replacement care).

Portsmouth Carers Service – Carers Breaks and Community Based Support

224. The Service offers a wide range of breaks to carers. Options include weekly coffee, break away, hair/beauty services, sports/crafting/hobby equipment, part payment for gym membership, kindle and TV subscriptions. Telecare/tech based solutions are also available and are promoted to carers.
225. Replacement care includes 6 hours a week sitting service or equivalent via direct payment, and two block purchased respite beds, chargeable at local authority rates for self-funders.
226. The Carers Service is tapping into community based support to help carers health and wellbeing. This includes cooking groups and support to access services such as Slimming World.

Carer Training

227. The NICE Guideline Supporting Adult Carers recommends that training should be offered to carers in how to provide care and support. Commissioners should ensure that the provision of carer training meets local needs and carers should be involved in the design and delivery of carer training to ensure it covers skills and expertise relevant to them.¹⁸
228. Where a young carer is providing care training needs to be co-designed with young carers so it is age appropriate.
229. Surrey provides training for carers, including a course on moving and handling. Emily Holzhausen OBE, Director of Policy at Carers UK, identified a range of different learning and development resources for carers, including digital resources that could be promoted in Southampton.

Recommendations to improve support for carers in Southampton

230. Progress is being made in Southampton. The move to a personalised approach, working with carers to identify their individual needs and options/solutions to meet those needs, utilising the strengths of a carers own social networks and what's available in their neighbourhood is the way forward.
231. Social prescribers, Health Coaches and Care Co-ordinators will assist with the personalisation approach for carers providing accessible support to carers.
232. However, too many carers at present are not in receipt of an assessment and are not receiving support services, carers breaks/replacement care or training. The infrastructure and range of community options is not yet in place to provide the broader model of support that carers would benefit from.
233. To help address the challenges identified the following actions are recommended:

1. Embed the strengths based approach to assessment and care planning into practice in Adult Social Care.
2. Learning from the examples of Surrey and Portsmouth, utilising community assets, work with carers to develop a broader offer of breaks and activities that can provide support to carers in their caring role and to have a life outside of their caring role. Support should be accessible to an increased number of carers recognising the health and wellbeing benefits to carers of early intervention and support.
3. With carers, review the provision of training for carers, including training on carers rights, to ensure that it meets their needs.
4. Consider how carers can be involved in the City of Culture Bid planning and celebrations.

¹⁸ NICE guideline – Supporting Adult Carers (Jan 2020) <https://www.nice.org.uk/guidance/ng150> - p24

Support to help carers stay in, enter or return to work, education and training

Young carers in education

234. Balancing education and care can be difficult. Young carers on average achieve one grade lower across all subjects than their peers at GCSE.¹⁹
235. In the earlier section focussing on 'identifying carers' the value of the Young Carers in Schools programme, an England-wide initiative that equips schools to increase identification of, and improve outcomes for, young carers in schools was recognised. The promotion of this initiative in Southampton schools is a recommendation of the Panel.

Working Carers

236. A 2019 Carers UK report, '*Juggling Work and Unpaid Care*', identified that there may be as many as 4.87 million working unpaid carers in the UK. This is 1 in 7 of all workers.
237. Many carers experience substantial challenges in balancing employment and their caring responsibilities. The 2019 Carers UK report indicates that the number giving up work to care has increased from 2.3 million in 2013 to 2.6 million in 2019.
238. Taking on a caring role should not mean that people have to give up work to care, potentially leading to financial hardship and/or social exclusion. Carers who want to work should be enabled to do so and should not be discriminated against. They should be supported in the workplace to maintain their employment status.

Southampton Carers experiences of balancing work and caring

239. The Panel heard from Vickey and Jon and their experiences differed greatly. Vickey had to leave her job as a physio to care for her son. She was unable to combine her caring responsibilities with work. Her employer was not very supportive and she was overlooked for opportunities, alienated by her team and left out of social activities.
240. Jon's manager was excellent and supported him in his caring role. The company were flexible with him and his productivity in work was not impacted. He was able to work and provide care until he had to focus on caring for his mum. Following her passing he was able to return to employment with the same employer via an employment agency.
241. Feedback provided by carers via Carers In Southampton has included the following quotes:
- *'If I didn't have this caring role I would have a good job and financial security. Instead I have to get flexible, zero hours work. Every year I feel more impoverished.'*
 - *'I need a lot of flexibility from my employers and unfortunately in the past this has been an issue that has caused me to lose my job.'*

Carers UK – Employment for Carers

¹⁹ The Children's Society (2013): Hidden from View

- 242. Carers UK have set up Employers for Carers (EfC), this is Carers UK's business forum. There are over 220 members representing 3.5m employees.
- 243. The forum seeks to support employers to develop carer friendly workplaces; promote the business benefits of supporting carers; and, influence employment policy and practice.
- 244. To help local authorities reach and support working carers in their community, EfC has an umbrella membership scheme. Local authorities sign up as the key subscriber and then make EfC's resources available free to health partners and SMEs in their area. The cost for local authority membership is circa £5-6k.
- 245. In January 2020 EfC launched the Carer Confident benchmarking scheme. The scheme supports employers build a positive and inclusive workplace for staff who are, or will become, carers and to make the most of the talents that carers can bring to your workplace.
- 246. There are three levels that any organisation, whether they are an EFC member or not, can achieve. Level one shows they are an active in addressing carer support, Level 2 shows that they are accomplished in providing carer support, and Level 3 shows they are an ambassador for carer support both internally and externally.
- 247. The certificate of achievement will be presented to employers who demonstrate they have built a positive and inclusive workplace where carers are recognised, respected and supported. No employer in Southampton has signed up to the Carer Confident scheme yet.
- 248. Where organisations have moved toward 'Carer friendly' employment practice they have been able to demonstrate strong business benefits such as significant savings made in unplanned absences and improved employee retention.²⁰

MYTIME Young Carers – Employability Programme

- 249. Despite their skillset, emotional maturity and additional acquired qualities, young adult carers are significantly more likely than their peers to end up NEET (not in employment, education or training).²¹
- 250. A number of areas provide specific support to help young carers approaching adulthood in regard to education, employment and independence.
- 251. To enhance employment prospects, MYTIME Young Carers in Dorset, launched an employability programme for young adult carers prior to the March 2020 lockdown.
- 252. Six young adult carers enrolled on the pilot programme led by a careers advisor. There was support from the business community who helped to facilitate activities such as mock interviews, mentoring and developing CVs. Some activities were impacted by the pandemic but the initial outcomes have been encouraging. One young adult carer who was formerly NEET is now in employment, three are now in education, and two are still working with MYTIME.
- 253. MYTIME Young Carers are looking to increase the scale of the employability programme. If this programme was piloted in Southampton there is the opportunity

²⁰ <http://www.employersforcarers.org/carers-confident>

²¹ The Children's Society (2013): Hidden from View

for this initiative to link with the Youth Hub that has been established in partnership between the DWP and Southampton City Council, and the support provided by No Limits to young carers. Collectively this could help to reduce NEET levels for young carers and could help support young carers transitioning into adulthood.

Recommendations to help carers stay in, enter or return to work, education and training

254. Too many carers are not in employment as a result of their caring responsibilities. Taking on a caring role should not mean that people have to give up work to care or limit their employment prospects.
255. By building a positive and inclusive workplace for all staff, including the growing numbers who are, or will become carers, businesses can support carers to remain in employment. This is both good employment practice and good business sense.
256. Initiatives such as the MYTIME Young Carers employability programme and the work of Employment for Carers have demonstrated that with the right support and encouragement more carers can be supported to stay in, enter or return to work.
257. To help address the challenges identified the following actions are recommended:

1. Sign up to the Employment for Carers umbrella membership scheme and work with Carers UK to promote the available resources to businesses in Southampton.
2. To enhance the City Council's reputation as a carer friendly employer, seek accreditation to the Carer Confident Scheme.
3. As part of the movement to embed social value into the procurement process, encourage suppliers to the Council to become accredited to the Carer Confident Scheme.
4. Pilot the MYTIME Young Carers employability programme in Southampton and explore opportunities to embed this within the work of the recently established Youth Hub developed in partnership with the DWP, and the work being delivered by No Limits. Collectively this could help to reduce NEET levels for young carers and could help support young carers transitioning into adulthood.

Key Step 4 - Involvement

- Advice is given to carer about the partnership approach to delivering care where the patient, carer and health and social care professionals are all seen as equal partners

258. In the 2018-20 National Carers Action Plan, reflecting feedback from carers, it is recognised that carers often have extensive contact with the health and social care system. Carers highlighted the importance of having their expertise recognised by the people they interact with in these services, so that their views are taken into account in decision making.²²
259. Carers value being recognised and respected as core members of the team around the person they care for.
260. This is recognised within the Personalised Care approach, a key priority in the NHS Long Term Plan. In her presentation to the Panel, Alison Froude – Delivery Partner in the Personalised Care Group at NHS England and Improvement, referenced that - *‘If the person they care for has a Personalised Care and Support Plan the carers should be fully involved, as far as the person wants them to be.’*

Figure 4 - Key elements of Personalised Care



261. Involvement should extend to including carers in the design, implementation and monitoring of services carers require. This is commonly referred to as co-production or co-design.
262. The Panel were informed about good practice in involving carers in Southampton. The Co-ordinator of the Southampton Parent-Carer Forum valued the approach to co-production from the City Council’s SEND service.
263. NHS providers outlined their commitment to involving carers. Solent NHS Trust has five commitment to carers. These include commitments to:
- Listen and hear carers – what really matters most
 - Involve carers in decisions related to care and treatment.
264. University Hospital Southampton NHS Foundation Trust (UHS) have appointed a carers experience lead post and created a carers working group. They have identified three objectives in their draft Carers Strategy, one of which is:
- Working collaboratively with and for carers - We will ensure that carers are recognised as care experts and are fully integrated and involved in care

²²Carers Action Plan 2018-2020: Supporting Carers Today, DHSC, p10

planning and decision making. We will work to ensure carer voices are heard and influence service development and improvement. We will also work with our colleagues across the health and care system to better support carers.²³

265. Southern Health NHS Foundation Trust have been developing their approach to involving carers over a period of time. They actively co-produce services and booklets with carers and look for opportunities to involve and engage with carers wherever possible. Fundamental to their approach is Southern Health's Carers Principles:

- Principle 1- We will recognise and respond to your own needs as a family member, carer or young carer
- Principle 2 - We will recognise your expertise, knowledge and important role that you play
- Principle 3 - We will welcome your involvement in the care of your family member/friend
- Principle 4 - We will value your involvement in the development of our services.

266. Feedback provided to the Inquiry Panel on involving carers has been mixed. Young carers and adult carers both identified the lack of recognition and engagement from health services, especially in primary care.

267. The SEND Service Manager at Southampton City Council was singled out for praise by a parent carer for the approach to co-production by the service:

- *'I think we are incredibly lucky in Southampton in that the service head is a Parent Carer herself and so she is very pro-Parent Carers, she is very receptive, she is very understanding and supportive of us. I actually think in Southampton, we're much luckier in that than many other areas that co-production is easier.'*

268. Comments received by Carers In Southampton from carers include:

- *'In respect to being a carer for my mum this isn't acknowledged at all by either GP, my son's care team or my mum's care team.'*
- *'Difficult to get GP to consistently listen to needs, some staff are brilliant but others are rubbish. Podiatrists are lovely. Sensory services were good.'*

Developments in Southampton to improve the involvement of carers

269. At meetings of the Inquiry Panel, information relating to initiatives in train, or planned for Southampton, that could help to improve the involvement of carers was considered. A number of these initiatives have been outlined below.

Triangle of Care

270. Southern Health is working towards accreditation for the Triangle of Care initiative. The Triangle of Care is a membership scheme promoting shared working between

²³ <https://www.carersinsouthampton.co.uk/Handlers/Download.ashx?IDMF=279b8d4e-74cf-4f23-a119-28c5b95c0f1f>

carers, professionals and people using services. It has produced a national set of good practice guidelines and a voluntary accreditation scheme with versions for adult carers, parent carers and young carers.

271. UHS are also planning to use the standards set out in the Triangle of Care accreditation scheme to benchmark support for carers.

WASP (Wessex Activation and Self-Management Programme)

272. WASP is a clinically led collaborative. Its aim is to support the implementation and spread of personalised care in Hampshire and Dorset.

273. Personalised care means people have more choice and control over the way in which their care is planned and delivered, it relies on new relationships and a change in the way the NHS works.

274. WASP is encouraging behaviour change across the health system with a shift away from a medical model to a collaborative model, involving patients and carers.

Involving carers – What does good look like?

275. NICE guidance on working with and involving carers says that:

- Health and social care organisations should promote ways of working with carers that acknowledge them as expert partners in care and value their skills and knowledge about the person they care for. These approaches should be incorporated into formal policies and processes.
- Health and social care practitioners should work in partnership with carers and treat them as a valued member of the care team around the person being cared for, with the person's consent. This should include involving carers in decision making and care planning & keeping them up to date.²⁴

Recommendations to improve the involvement of carers

276. Carers have valuable information to contribute to care planning and assessments, they are often key to understanding the person's needs and preferences, and their involvement should be encouraged and supported. Evidence provided to the Panel suggests that this is not happening consistently across all settings.

277. Personalised care, and its implementation by NHS providers in Southampton, gives encouragement and should, alongside the adoption of GP Carer Quality Markers recommended in Key Step 1, address the consistency issues raised. The ambition of NHS providers with regards to involving carers is also welcomed.

278. A number of positive examples of co-production / co-design with carers have been identified. Co-production helps to ensure that resources are used wisely to develop the services that carers really want and need.

279. To help address the challenges identified the following actions are recommended:

1. Embed the practice of working in co-production with carers and people with lived experience, as well as other stakeholders, to ensure they are involved in the development, design and provision of services to meet their real needs.

²⁴ <https://www.nice.org.uk/guidance/ng150/chapter/Recommendations#information-and-support-for-carers-overarching-principles>

Key Step 5 - Transition

- Carers have a seamless experience when moving through the service

280. As reference by Emily Holzhausen OBE, Policy Director at Carers UK, the caring journey is rarely static. There are potentially many stages of transition, young carer to adult carer, parent carers will similarly transition into caring roles for their adult children, transition from hospital, care homes, hospices. The assistance they need can be expected to change as they pass through different stages and experience changes during their caring journey.
281. To make transitions as smooth as possible the NICE adult care guideline recommends the provision of information and emotional and practical support to help carers prepare for and adjust to changes in their role, for example if the person they care for:
- makes the transition to adult services
 - moves away from home
 - has a significant change in their health
 - becomes terminally ill or needs end of life care
 - dies unexpectedly.
282. In the Carers Action Plan 2018-2020, to support the transition for young adult carers, Government committed to seeking to identify and disseminate effective approaches to transition assessments that will translate into support that enables young adult carers to make positive transitions between the ages of 16-24. The identified delivery date for this was 2018/19. If this has action has been completed I have not been able to locate this guidance.
283. The Panel did not receive much information about carers transitions. The issue of transitioning was raised by No Limits in their evidence submitted to the inquiry. They identified challenges relating to specialist transition support for young carers over 16.
284. The Panel were also made aware that Carers in Southampton supports carers in moving towards a life after caring with regular support sessions. This service is welcomed by adult carers.
285. Without specific details on existing transition support being provided in Southampton, the Panel encourages the following of the NICE guidelines to support carers as they transition between stages on their caring journey, and that statutory transition assessments, outlined in Key Step 3a), are undertaken in accordance with identified best practice.

Co-ordination and Prioritising Carers

286. Moving away from the Surrey Carers Pathway, at meetings of the Inquiry Panel a number of issues have consistently been raised by carers that limit the effectiveness of efforts to improve outcomes for carers in Southampton.
287. The Panel recognise that there are numerous actions and initiatives that are being delivered in Southampton that will be of benefit to carers and have been designed with the best interests of carers in mind. However, what is apparent is that there is not always a co-ordinated approach that considers how the initiatives or actions will work as part of the carers pathway.
288. This is perhaps best demonstrated by the various carers identification approaches being utilised by the three NHS providers in Southampton. Each approach is to be applauded but each has a different solution. Carers often have to navigate between NHS providers, a single solution, agreed collectively by providers would reduce duplication, reduce confusion and make it easier for carers to navigate and understand. Carers suffer when services do not work together effectively.
289. A similar complaint that was often raised was the requirement to repeat details to each and every service provider and the inability of systems to interact effectively.
290. A 2016 report from the NHS stated that:
- 'We understand that the biggest risk to Carers is the failure to share information sensibly. We will work to remove burden of Carers having to repeat information and will reduce the barriers to effective sharing of information. Improved sharing of information will help to identify vulnerable Carers earlier, improve the identification of Carers and the assessment of their support needs, and could improve the responsiveness of support to the changing needs of Carers.'²⁵
291. Across Hampshire a secure system called the Care and Health Information Exchange (CHIE) shares health and social care information from GP surgeries, hospitals, community and mental health, social services and others.
292. Carers UK have produced a package of support for carers which local authorities can purchase. It is then freely available to all carers in their area. 'Digital Resource for Carers' includes the Jointly app which is designed to share information with people the carer registers on the app, digital training and other support.
293. To improve co-ordination of support for carers, and with carers, the following actions are recommended:

1. Develop a Carers Charter that all organisations that work with carers can adopt and promote its principles. Hampshire Carers Charter, developed with carers, is based on the four key principles for supporting carers that has subsequently been adopted by Southern Health.
2. Establish a carer led Southampton Carers Partnership to ensure that the views of carers are listened to and to improve the effectiveness of multi-agency working in achieving outcomes for carers based on priorities they have said make a real difference to them.

²⁵ An integrated approach to identifying and assessing Carer health and wellbeing, NHS – May 2016, p35

294. To improve the sharing of data and intelligence to support carers, the following actions are recommended:

1. Explore how the Care and Health Information Exchange (CHIE) can be improved in design or usage, to enable carers to only tell it once and for relevant services to have timely access to carers emergency plans.
2. Purchase access to Carers UK 'Digital Resource for Carers'. This would give all carers in Southampton free access to training, the Jointly app designed by Carers UK to help store and to share information and manage care and other digital support.

Prioritising carers

295. In recognition of the integral part carers play in our health and social care system, and the challenges carers face, some local authorities and CCGs have sought to ensure that the impact on carers is considered when major policy changes are proposed.

296. Equality impact assessments provide a way for a council or commissioners to consider impact on different groups protected from discrimination by The Equality Act 2010. They also help councils consider how best to provide help and support to those who need it most and to plan services that are as accessible and fair as possible.

297. Equality impact assessments are usually carried out when a new service is developed, there is a review of a service or a major policy change. Their findings are considered by decision makers. This is to make sure decisions, policies or procedures do not have unintended consequences for people with protected characteristics.

298. At Hertfordshire County Council carers have been included as a protected group.

Monitoring progress

299. As with the development of all new approaches and objectives, there needs to be a mechanism for measuring progress made in the effectiveness of support provided to carers in Southampton, and to hold decision makers to account.

300. To measure progress in delivering improved outcomes for carers and to recognise the contribution carers play in our health and care system the following actions are recommended:

1. Southampton City Council adopts carers as a protected group requiring the Council to make sure decisions, policies or procedures do not have unintended consequences for carers.
2. Develop a dashboard of appropriate metrics to measure and monitor the outcomes for carers in Southampton. Progress should be considered regularly by the Better Care Board.

Conclusions and Recommendations

301. A summary of the key evidence presented at each of the inquiry meetings is attached as Appendix 3. All the reports, presentations and minutes from the inquiry meetings can be found here:
<http://www.southampton.gov.uk/modernGov/ieListMeetings.aspx?CId=750&Year=0>

Conclusions

302. Carers are essential. They make an enormous contribution to the people they support and are an integral part of our health and social care system. To the people they help, they are the indispensable family members, friends, and neighbours that make each day possible. In Southampton they are vital partners, bridging the gap between local health and care services.
303. Caring can have a considerable impact on the mental and physical health of carers, their employment prospects and many carers experience financial difficulties due to their caring role.
304. Carers have been hit particularly hard by the COVID-19 pandemic. The closure of support services has resulted in many carers not being able to take a break from their caring role, increasing their isolation and the burden and pressure on them.
305. Carers have their own needs too, and, throughout the inquiry, the Panel have been made aware of the increasing commitment from health, care and voluntary organisations in the city to address the needs of carers and this has been matched with action designed to improve outcomes for Southampton's carers.
306. However, despite improvements being made, in Southampton there are currently:
- Too many carers that have not been identified and are not known to carer organisations or health and care providers.
 - Too few carers receiving timely assessments of their needs.
 - Too few carers in receipt of help to support them in their caring role and to live a life outside their caring role.
 - Too many carers that are having to leave work to care or are having their prospects damaged by the impact of their caring duties on their educational attainment.
307. The Panel have been informed about developments planned, or in the process of being implemented that will improve outcomes for carers. In particular, personalised care, if applied consistently and equitably across the health and care system, offers an opportunity to put the individual and their families, including carers, at the centre of the process, shifting relationships between health and care professionals and people.
308. It is clear that a number of other areas are more advanced in their approach to supporting carers than we are in Southampton. In particular the Panel were impressed by the example shown by Surrey which demonstrates what can be achieved by leadership, integration across health and care services, dedication, resources and perseverance.
309. Improving outcomes and support for carers will not happen overnight. It takes time but it can be done. In improving outcomes we must be cognisant of the

importance of genuine partnership working, early intervention and prevention, and involving carers at every stage of the journey.

310. The challenge is difficult, and if we are successful in identifying more carers, solutions will need to be found to bolstering our carers services and statutory services to meet the demand for assessments, care planning and support services. Evidence suggests that investment in carers' services to support them in their caring role is financially beneficial for social care and sees a significant return on any investment made.²⁶
311. No single organisation has all the solutions and the solutions cannot all come from statutory services. We should endeavour to identify and engage with all carers. However, many carers have little contact with services for carers and are not receiving formal support in their caring role, for these carers it is vital that we work with partners beyond health and care organisations to raise awareness of caring among the wider population to build a carer friendly community in Southampton.

Recommendations

312. In this report the recommendations have been identified for each key step in the carers pathway. In summary, reflecting the key findings and conclusions the following actions are recommended to help improve support for carers in Southampton:

To identify more carers:

1. Encourage and support primary care providers in Southampton to become more carer aware by adopting the GP Carer Quality Marker.
2. Akin to the Surrey Carers Workforce Task Group, to lead by example, promote the identification and support for carers employed within the City Council and NHS providers operating in Southampton.
3. Promote the Young Carers in Schools Programme within Southampton's schools and empower schools to identify and support young carers.
4. In conjunction with young carers, establish a Southampton Young Carers Identification Card and seek the support of appropriate organisations to offer discounts to our young carers.
5. Support the identification of a community hub/venue which makes it easier for carers to access support when needed.

To improve information, advice and guidance:

6. Develop formal processes to encourage regular communication between the providers of carers information, advice and guidance in Southampton. Thereby duplication is minimised, advice is consistent, the no wrong door approach is applied and carers, or advocates, can navigate the system easily.

To improve assessments:

7. Review the process for undertaking parent-carer assessments to ensure that all parent-carers who have an appearance of need, or request one, have access to

²⁶ <https://www.local.gov.uk/sites/default/files/documents/economic-case-investment--7a4.pdf>

the statutory assessment, and, that they are actively involved in the assessment.

8. Incorporate the principles being applied in Portsmouth to the assessments being undertaken by carer organisations in Southampton.

To improve support for carers in Southampton:

9. Embed the strengths based approach to assessment and care planning into practice in Adult Social Care.
10. Learning from the examples of Surrey and Portsmouth, utilising community assets, work with carers to develop a broader offer of breaks and activities that can provide support to carers in their caring role and to have a life outside of their caring role. Support should be accessible to an increased number of carers recognising the health and wellbeing benefits to carers of early intervention and support.
11. With carers, review the provision of training for carers to ensure that it meets their needs.
12. Consider how carers can be involved in the City of Culture Bid planning and celebrations.

To help carers stay in, enter or return to work, education and training:

13. Sign up to the Employment for Carers umbrella membership scheme and work with Carers UK to promote the available resources to businesses in Southampton.
14. To enhance the City Council's reputation as a carer friendly employer, seek accreditation to the Carer Confident Scheme.
15. As part of the movement to embed social value into the procurement process, encourage suppliers to the Council to become accredited to the Carer Confident Scheme.
16. Pilot the MYTIME Young Carers employability programme in Southampton and explore opportunities to embed this within the work of the recently established Youth Hub developed in partnership with the DWP, and the work being delivered by No Limits. Collectively this could help to reduce NEET levels for young carers and could help support young carers transitioning into adulthood.

To improve the involvement of carers:

17. Embed the practice of working in co-production with carers and people with lived experience, as well as other stakeholders, to ensure they are involved in the development, design and provision of services to meet their real needs.

To improve co-ordination of support for carers, and with carers:

18. Develop a Carers Charter that all organisations that work with carers can adopt and promote its principles. Hampshire Carers Charter is based on the four key principles for supporting carers adopted by Southern Health Foundation Trust.

19. Establish a carer led Southampton Carers Partnership to ensure that the views of carers are listened to and to improve the effectiveness of multi-agency working in achieving outcomes for carers based on priorities they have said make a real difference to them.

To improve the sharing of data and intelligence to support carers:

20. Explore how the Care and Health Information Exchange (CHIE) can be improved in design or usage, to enable carers to only tell it once and for relevant services to have timely access to carers emergency plans.
21. Purchase access to Carers UK 'Digital Resource for Carers'. This would give all carers in Southampton free access to training, the Jointly app designed by Carers UK to help store and to share information and manage care and other digital support.

To measure progress in delivering improved outcomes for carers and to recognise the contribution carers play in our health and care system:

22. Southampton City Council adopts carers as a protected group requiring the Council to make sure decisions, policies or procedures do not have unintended consequences for carers.
23. Develop a dashboard of appropriate metrics to measure and monitor the outcomes for carers in Southampton. Progress should be considered regularly by the Better Care Board.

Appendices

Appendix 1 – Inquiry Terms of Reference

Appendix 2 – Inquiry Plan

Appendix 3 – Summary of Key Evidence

Appendix 1 – Terms of Reference

Carer Friendly Southampton

1. Scrutiny Panel membership:

- Councillor Savage
- Councillor Coombs
- Councillor McEwing
- Councillor Prior
- Councillor White
- Councillor Windle
- Councillor B Harris

2. Purpose:

To identify opportunities to improve support for carers in Southampton.

3. Background:

- The Care Act 2014 defines a carer as ‘someone who helps another person, usually a relative or friend, in their day-to-day life. According to Carers UK, 6.5 million people are carers, supporting a loved one who is older, disabled or seriously ill across the UK
- Caring can have a huge effect on carers. Across the UK carers are holding families together, enabling loved ones to get the most out of life, making an enormous contribution to society and saving the economy billions of pounds. Yet many carers are struggling to juggle care with work and family life, or even suffering with poor health themselves.
- Carers UK have identified that many carers don’t know how or where to get help and that being a carer can be frightening and very lonely.
- There are estimated to be over 32,000 unpaid carers in Southampton.
- In 2016 a strategy that aimed to identify what is needed to improve the lives of carers now and in the future in Southampton, and to change services to meet those needs was produced. The Southampton Strategy for Unpaid Carers and Young Carers is due for renewal in January 2021.
- Across the UK, there are examples of local approaches that are improving the lives of carers.

4. Objectives:

- a. To review progress being made in Southampton to support carers.
- b. To identify good practice being employed to support carers elsewhere.
- c. To identify what initiatives could work well in Southampton to help support carers.

5. Methodology:

- a. Seek the views of carers and stakeholders
- b. Undertake desktop research
- c. Identify best practice

6. Proposed Timetable:

Seven meetings between October 2020 and April 2021.

7. Draft Inquiry Plan (subject to the availability of speakers)

Meeting 1: 8 October 2020

- Introduction, context and background
 - Overview of national position
 - Overview of current position in Southampton.

To be invited:

- Cabinet Member for Health & Adult Care
- Carers UK
- Carers in Southampton
- Carers Together

Meeting 2: 5 November 2020

- Carers health, wellbeing and safety
 - Time for yourself and isolation
 - Health & wellbeing, including mental health needs
 - Relationship support (family dynamics) and experience of loss

To be invited:

- To be confirmed

Meeting 3: 26 November 2020

- Carers identification rights, recognition and support
 - Role of professionals to identify
 - Self-identity
 - Planning for emergencies
 - Access and quality of respite or replacement care, planned and unplanned breaks

To be invited:

- To be confirmed

Meeting 4: 7 January 2021

- Access to information, advice and guidance
 - Financial support and the DWP
 - Access to practical support and help from the community
 - Housing and adaptations issues

To be invited:

- To be confirmed

Meeting 5: 28 January 2021

- Support to carers
 - Access to health and social care services in the caring role
 - Information advice and guidance for the caring role
 - Support and training for a carer

To be invited:

- To be confirmed

Meeting 6: 25 February 2021

- Support in education and work
 - Young carers protected and supported to learn and thrive
 - Opportunities and challenges in work and education
 - Access and availability for transport to support the caring role

To be invited:

- To be confirmed

Meeting 7: 8 April 2021

To approve the final report of the inquiry and recommendations.

Appendix 2 - Inquiry Plan

DATE	MEETING THEME	EVIDENCE PROVIDED BY
08/10/20	Agree Terms of Reference and introduction to the inquiry	<ul style="list-style-type: none"> • Emily Holzhausen OBE - Director of Policy and Public Affairs, Carers UK • Adrian Littlemore - Senior Commissioner, Integrated Commissioning Unit • Linda Lawless – Service Manager, Carers in Southampton • Michelle Young – Project Manager, No Limits • Anne Meader – Member of the Board of Trustees, Carers Together • Cllr Fielker – Cabinet Member for Health & Adult Care
05/11/20	Carers health, wellbeing and safety	<ul style="list-style-type: none"> • Carers - Rebecca Kinge, Alex, Leah, Jasmine and Zunayrah • Clare Rachwal, Team Manager, Portsmouth Carers Centre • Sarah Balchin, - Associate Director Patient Experience, Solent NHS Trust • Dawn Buck - Head of Patient and Public Engagement and Patient Experience, Southern Health NHS Trust • Amelia Abbott, Patient and Public Engagement – Southern Health NHS Foundation Trust • Sharon Stewart, Head of Service for Adult Social Care, SCC • Louise Ryan, Service Manager for Social Well-Being, SCC
26/11/20	Carers identification rights, recognition and support	<ul style="list-style-type: none"> • Carers – Laura, Jenny, Ellie-May, Leah and Zunayrah • Debbie Hustings - Partnership Manager (Carers) Surrey Heartlands Integrated Care System • Dr Karen Malone, GP at Old Fire Station Surgery in Woolston • Ellis Banfield, Head of Experience & Involvement, University Hospital Southampton NHS Foundation Trust (UHS) • Dawn Buck, Head of Patient and Public Engagement and Patient Experience - Southern Health NHS Foundation Trust • Sharon Stewart, Head of Service for Adult Social Care, SCC • Louise Ryan, Service Manager for Social Well-Being, SCC

DATE	MEETING THEME	EVIDENCE PROVIDED BY
		<ul style="list-style-type: none"> • Laura Vicinanza, Regional Public Affairs and Campaigns Officer, Alzheimer's Society (written evidence)
07/01/21	Carers access to information, advice and guidance	<ul style="list-style-type: none"> • Carers - Ellie-May, Leah, Zunayrah and Jenny • Mark Knight, DWP Policy Lead for Carers • Andy Sherman, DWP Employer & Partnership Manager • Emily Holzhausen OBE, Director of Policy and Public Affairs at Carers UK • James Marshall, Head of Customer and Communications, SCC • Lisa Haynes, Head of Supported Housing and Community Support, SCC • Liz Donegan, Chief Officer at Citizens Advice Southampton • Nicky Judd, SO:Linked Programme Manager at Southampton Voluntary Services • Gary Walker, Alzheimer's Society Manager
28/01/21	Carers support in education and work	<ul style="list-style-type: none"> • Carers - Alex, Ellie-May, Leah, Zunayrah, Vickey and Jon • Rebecca Rolfe, Service Manager for the Include Service at The Children's Society • Krista Sharp, CEO, MYTime Young Carers • Charlie Dormehl, Teacher of History • Hattie Wheeler & Anna Aksenova, 6th formers at King Edwards VI School, Southampton • Katie Cope, HR Advisory Manager, SCC • Madeleine Starr MBE, Director of Business Development and Innovation and Katherine Wilson, Head of Employers for Carers at Carers UK (written evidence)
25/02/21	Supporting carers in their caring role	<ul style="list-style-type: none"> • Carers - Alex, Ellie-May, Leah, Zunayrah, Claire • Lee Culhane, Hampshire Young Carers Alliance • Alison Froude, Delivery Partner, Personalised Care Group, NHS England & Improvement • Moraig Forrest-Charde, Deputy Associate Director, Integrated Commissioning Unit • Louise Ryan, Service Manager for the Social Wellbeing Service, SCC • Carl Adams - Head of People Participation/ Clinical lead Community Specialist Service, Solent NHS Trust • Vickey Kowal, Co-ordinator of the Southampton Parent Carer Forum

DATE	MEETING THEME	EVIDENCE PROVIDED BY
		<ul style="list-style-type: none"> <li data-bbox="651 271 1362 338">• Jo Payne & Emma Bowley - No Limits (Written evidence)
08/04/21	Agree final report	

The minutes for each meeting, the evidence submitted to the Scrutiny Inquiry Panel and presentations delivered at each meeting is available at: -

<http://www.southampton.gov.uk/modernGov/ieListMeetings.aspx?CId=727&Year=0>

Appendix 3 – Summary of key evidence

Key evidence provided to the Inquiry Panel at each meeting can be accessed via the following link:

http://www.southampton.gov.uk/images/appendix-3%20summary-of-key-evidence_tcm63-440845.pdf