

No Longer Able to Care:

Supporting older
carers and ageing
parent carers to plan
for a future when they
are less able or unable
to care

About the VCSE Health and Wellbeing Alliance

The Voluntary Community and Social Enterprise (VCSE) Health and Wellbeing Alliance (HW Alliance) is a key element of the Health and Wellbeing Programme. The HW Alliance is a partnership between voluntary sectors and the health and care system to provide a voice and improve health and wellbeing for all communities. Carers Trust, with Carers UK, form the Carers Partnership as members of the HW Alliance. All partners in this project are members of the HW Alliance, either as individual organisations or as partnerships.

The HW Alliance has been established to:

- Facilitate integrated working between the voluntary and statutory sectors.
- Support a two-way flow of information between communities, the VCSE sector and policy leads.
- Amplify the voice of the VCSE sector and people with lived experience to inform national policy.
- Facilitate co-produced solutions to promote equality and reduce health inequalities.

The HW Alliance is jointly managed by the Department of Health and Social Care (DHSC), Public Health England (PHE) and NHS England and is made up of 20 VCSE Members that represent communities who share protected characteristics or that experience health inequality. Through their networks, HW Alliance Members can link with communities and VCSE organisations across England¹.

Carers Trust worked with the following project partners from the HW Alliance:

- Association of Mental Health Providers.
- Carers UK (Carers Trust and Carers UK form the Carers Partnership).
- Citizens Advice.
- Complex Needs Consortium.
- FaithAction.
- Friends, Families and Travellers.
- The National LGBT&T Partnership.
- The Valuing People Alliance.

¹<https://www.england.nhs.uk/hwalliance/>

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The Coronavirus crisis

This report was finalised during the Coronavirus crisis, which started in England in early 2020.

The Coronavirus Act 2020 (CVA) gave local authorities the ability to 'ease' many of the duties contained in the **Care Act 2014** to powers. These easements aim to enable local authorities to meet growing pressures because of the Coronavirus crisis and to prioritise services. Statutory Guidance issued under the Coronavirus Act made it clear that local authorities should only apply temporary easements when the workforce is significantly depleted, or demand on social care increased to an extent that it is no longer reasonable for them to comply with its duties under the Care Act, and continuing to comply may result in urgent and acute needs not being met.

The CVA Statutory Guidance³ also makes it clear that local authorities retain the ability to assess and support carers, and the person they care for. They should also do all they can to continue meeting their existing duties under the Care Act 2014.

This report and resources are finalised under the assumption that the Care Act will be fully re-instated after the Coronavirus crisis is declared over by the Government.

We do not yet know the impact this crisis will have in the medium and long term. In the short term, we know the crisis is having an impact on unpaid carers, and the people they care for. Some carers will have had increased support from other family and friends during the crisis. Many carers and the people they care for will be at greater risk of severe illness. Many carers will be under even more pressure than usual, having to increase their caring responsibilities, and worried both about themselves and the person or people they care for getting Coronavirus.

The report and resource are about planning for the longer term when carers are less able or unable to care. However, one of the findings is that conversations about shorter term emergency planning can be a useful way of opening up discussions about the longer-term future.

This crisis has highlighted the importance of emergency planning as all carers will have to make changes to account for the Coronavirus emergency.

Once the crisis is declared over, and the Care Act is fully re-instated, national and local partners from across the sectors must work together to ensure unpaid carers are properly supported to plan for a future when they are less able or unable to care.

²<http://www.legislation.gov.uk/ukpga/2020/7/contents/enacted/data.htm>

³<https://www.gov.uk/government/publications/coronavirus-covid-19-changes-to-the-care-act-2014/care-act-easements-guidance-for-local-authorities>

Executive summary

This report highlights how older parent carers and ageing carers who face additional barriers to receiving services should be supported to prepare for a time when they are less able or unable to provide care⁴.

Most unpaid carers will need support to continue caring for as long as they want to. This support will be different at different stages of their caring journeys and should be tailored according to their needs and identity. Services should be open and accessible to all carers, no matter what different communities carers may identify with. Some carers from some communities may prefer and need support from specialist services, and this support should be provided.

Partners in this project looked at one stage of caring: support for carers preparing for changing circumstances when they are, or will be, less able, or unable, to care. This report is about supporting older carers and ageing parent carers. It is aimed at local and national decision makers, commissioners and service providers. For the purposes of this report, older and ageing carers are defined as carers over the age of 50.

This report looks at the evidence available about carers facing this change in circumstance. The report finds that most carers are not currently accessing the support they need to plan for a future when they are less able or unable to care.

The report uses existing evidence, evidence gathered from surveys of carers and service providers, focus groups with carers, and interviews with experts, to make the case for improvement for support for carers at this stage of their caring journey.

We highlight the impact that the social care funding crisis has on carers, the lack of confidence carers have in social care, as well as the lack of availability of social care. We make recommendations on what needs to be done by national decision makers, local commissioners, and service providers to support carers to plan for a future when they are less able or unable to care.

The trigger points that mean carers are less able or unable to care are varied. They may be linked to the carer's age, the carer's own health, or it may be that the condition of the person with care and support needs deteriorates to the extent that the carer is no longer able to provide the level of care required.

These trigger points are not normally single events. They can be understood to be progressive or take place at different stages of the caring journey or a carer's life, rather than a single event.

During these periods, carers may find that another family member or friend becomes more involved in caring responsibilities, it may be that statutory services take more of a leading role in providing care and support, or it may be that the person with care and support needs may move into independent living, supported accommodation or into a care home.

⁴While this report looks at the experience of carers living in England and the recommendations are focussed on the systems found in England, the lessons learned can be applied to the rest of the UK.

However, there should be no assumption that another family member or friend will take on caring responsibilities, and it's vital that caring is, and remains, a choice.

This report, in addition to analysing existing evidence, is based on:

- focus groups attended by 30 carers over the age of 50, and from different communities who face additional barriers to accessing services or ageing parent carers,
- a survey completed by 200 carers, and
- a survey completed by 50 care and support providers.

While the sample sizes are relatively small, they do all reinforce existing and developing evidence about the importance of this support, the current lack of support carers feel is available and the need for national and local decision makers, commissioners and service providers to act to ensure this support is available in the future.

The report is aimed at national and local decision makers, commissioners and other professionals who are interested in ensuring that unpaid carers are supported during this important stage of the caring journey.

Alongside this report, there are resources for commissioners, providers and front line staff, to help in the development of support for carers to plan for a future when they are less able or unable to care. Also included are resources that providers and front line staff can share with carers to encourage them to think about planning for the future, and to support carers in doing so.

Based on the evidence we collected, the report and resources also suggest a possible pathway that commissioners and providers could implement that works with carers from the point of identification, through to being supported to plan for a future when they are less able or unable to care.

Main findings of the report

Wider care and support system

- The majority of carers are not currently being supported to plan for a future when they are less able or unable to care.
- There is a wider lack of confidence in the social care system as a whole, meaning carers do not seek support.
- Carers also face the problem of the lack of available social care – both for themselves and the person they care for. This leads to many carers picking up more caring responsibilities, to the detriment of their health and wellbeing.
- Carers often feel too busy dealing with the day-to-day to think about planning for the future. Broader support for carers in the day-to-day challenges they face will enable services and individuals to better plan for the/their future.
- Some carers are given support to prepare for a crisis where they are unable to care in the short term and for a limited time period. While this is a positive step, much more needs to be done to plan for the long-term future where the carer is unable to care.

Communities who face additional barriers

- Some communities do not see health and social care, and some services provided by charities, as “for them”.
 - Often for statutory services this is due to previous bad experiences with the service where individuals have faced discrimination.
- Some carers from some communities want and require specialist support.
 - Some carers may benefit from support from organisations which are specialised in providing support with and for that community.
- All services should be accessible to all members of the population and services must be able to provide support to individuals who are from communities who currently face additional barriers to accessing services.

Trigger points for support

These ‘trigger’ points should be understood by commissioners, providers and carers themselves as different stages of a carer’s life or caring journey. The most common life stages at which carers will need support may be interlinked. The most common trigger points that carers, service providers and experts highlighted are:

- A change in the condition of the person they care for, meaning carers were less able or unable to care.
- Carers’ own health declining.
- Carers’ own age.
- Carers becoming physically unable to care.

The different stages of a carer’s journey should form the basis of long-term planning for a future where they are less able or unable to care. Good long-term planning will be preventative, more comprehensive than a crisis plan, and consider the needs and aspirations of both the carer and the person or people with care and support needs.

Recommendations

Central Government

- Statutory carers assessments are essential and not all carers are receiving them. This must be remedied if Government and commissioners want to support unpaid carers.
- The ADASS Budget Survey showed that many Directors of Adult Social Care Services do not have confidence that they have the funding to fulfil their duties under the Care Act⁵. Central Government must ensure that local authorities have appropriate levels of funding available to them to meet all Care Act duties.
 - Carers are entitled to a Carer's Assessment under the Care Act. This statutory assessment is meant to consider all a carer's support needs as a carer, and prevent further needs from developing.
- Central Government should encourage local authorities to develop local services to support carers to plan for the future when they are less able or unable to care.
 - As part of developing these services, carers and former carers should be involved in their planning, design and production.
- Questions about whether a person is a carer and their caring role should be rolled out in the NHS Health Check⁶.

⁵<https://www.adass.org.uk/adass-budget-survey-2019>

⁶<https://www.nhs.uk/conditions/nhs-health-check/>

Local authority commissioners

- Support for carers to plan for a future when they are less able or unable to care should be recognised as an important area for future service planning.
 - Contracts should encourage long term support for carers and not just outputs based on the number of carers supported. Carers must get the support they need at the time they need it.
- Local authorities must ensure there is early identification and support of carers. Without this, subsequent support to plan for a future when carers are less able or unable to care becomes more difficult.
 - Early identification allows carers to be supported at an earlier stage of their caring journey, be in contact with services and be more likely to be supported in the daily challenges of being a carer, therefore giving them the chance to plan for the future.
- Once a carer is identified, the support plan that is developed for the carer should consider trigger points or life stages when the carer may need more support. This should happen as early as possible.
- Organisations across the statutory and voluntary sector must work together to ensure carers get the support they need at this stage of their caring journey.
 - This will include partnership working between statutory organisations, as well as partnership working between charities and across sectors.
- Services, including voluntary and statutory services, should be open to all members of the community.
- Some communities who face additional barriers may prefer support from specialist organisations. The communities focussed on in this report are the Black, Asian and Minority Ethnic (BAME) communities, the Gypsy and Traveller communities and the Lesbian, Gay, Bisexual and Transgender (LGBT) communities. Other communities also face barriers to accessing services.
 - Service providers should have good knowledge of local specialist organisations so they can effectively signpost and co-work.
- Carers should be involved in the design of their support services.

Health, care and support providers

- Health, care and support providers must ensure there is early identification and support of carers. Without this, subsequent support to plan for a future when carers are less able or unable to care becomes more difficult.
 - Early identification allows carers to be supported at an earlier stage of their caring journey, be in contact with services and be more likely to be supported in the daily challenges of being a carer, therefore giving them the chance to plan for the future.
 - GPs can play a central role in identifying carers early and referring them for support.
- Once a carer is identified, the support plan that is developed for the carer should consider trigger points or life stages when the carer may need more support. This should happen as early as possible.
- Subsequent assessments, or re-assessments, should revisit these trigger points and have conversations with carers about how they view the future.
- Organisations across the statutory and voluntary sector must work together to ensure carers get the support they need at this stage of their caring journey.
 - This includes partnership working between statutory organisations, as well as partnership working between charities and across sectors.
- The NHS Health Check and Mid Life MOT⁷ should be better utilised as opportunities to identify carers and explore what plans need to be made for a future when they are less able or unable to care.
- Planning must take into account carers' own needs and circumstances separate from those of the person they care for.
 - Often this planning will involve another member of the family or friend taking on more, or all, of the caring responsibilities, however:
 - It is vital to highlight that there should be no assumption from Central Government, local commissioners or local service providers that another family member or friend will take on the caring role. Caring is, and should always remain, a choice; and conversations and planning should be grounded on this basis.
 - If a family member or friend is going to take on more caring responsibilities, that carer must also be identified, offered a carer's assessment and supported.
- The views, needs and aspirations of the person or people with care and support needs must also be jointly included in this planning, combined with carers' voices as expert partners in care. This should be enabled through co-planning between services, carers and the person with support needs.
- Services, including voluntary and statutory services, should be open to all members of the community.
- Some communities who face additional barriers may prefer support from specialist organisations. The communities focussed on in this report were from BAME, Gypsy and Traveller and LGBT communities. Other communities also face barriers to accessing services.
 - Service providers should have good knowledge of local specialist organisations so they can effectively signpost and co-work. Carers should be involved in the design of their support services.

⁷<https://www.yourpension.gov.uk/mid-life-mot/>

Front line staff

- Front line staff should ensure there is early identification and support of carers. Without this, subsequent support to plan for a future when carers are less able or unable to care becomes more difficult.
 - Early identification allows carers to be supported at an earlier stage of their caring journey, be in contact with services and be more likely to be supported in the daily challenges of being a carer, therefore giving them the chance to plan for the future.
- Once a carer is identified, the support plan that is developed for the carer should consider trigger points or life stages when the carer may need more support. This should happen as early as possible.
- The NHS Health Check and Mid Life MOT should be better utilised as opportunities to identify carers and explore what plans need to be made for a future when they are less able or unable to care.
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- Services, including voluntary and statutory services, should be open to all members of the community.
- Some communities who face additional barriers *may* prefer support from specialist organisations. The communities focussed on in this report were from BAME, Gypsy and Traveller and LGBT communities. Other communities also face barriers to accessing services.
 - Service providers should have good knowledge of local specialist organisations so they can effectively signpost and co-work.

Introduction

The project: Carers becoming less able or unable to care

Carers Trust were commissioned by the Department for Health and Social Care to lead this project, working with VCSE organisations in the Health and Wellbeing Alliance, focussing on older and ageing carers aged over 50 and in particular:

- Ageing parent carers
- Other community groups of older and ageing carers who face additional barriers

whose changing circumstances mean they are less able to care or unable to continue caring at all.

Who are carers?

A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.

Who are parent carers?

A parent carer is someone over 18 and provides unpaid care to a child (who can be over the age of 18) for whom they have parental responsibility.

The project aims to find out how older parent carers and ageing carers from groups who face additional barriers to receiving services are being supported to prepare for a time when they are less able or unable to provide care. Older carers for the purposes of this project are defined as carers over the age of 50. The age of 50 was set due to health inequalities faced by the Irish Traveller community – 30% of whom die before the age of 60⁸.

The other community groups of older and ageing carers who face additional barriers that the project focussed on are carers from the:

- Black, Asian and Minority Ethnic (BAME) communities.
- Gypsy and Traveller communities (many of whom are also considered minority ethnic groups).
- Lesbian, Gay, Bisexual and Transgender (LGBT) communities.

We know that these communities face existing barriers to accessing health and care services.

⁸<https://www.ons.gov.uk/>

It should be highlighted that Romany Gypsies and Irish Travellers are recognised by law as ethnic groups and are therefore also considered BAME groups⁹. This means that they are protected by the Equality Act and public bodies have responsibilities to them under the Public Sector Equality Duty. Many public bodies are failing to do this, with the Women and Equalities Select Committee recently concluding that ‘the Public Sector Equality Duty is clear that public bodies have a duty to have due regard to advancing equality and fostering good relations between protected groups. We have found a conspicuous lack of due regard for the needs of the Gypsy, Roma and Traveller communities which we believe leads to the very poor outcomes outlined above¹⁰.’

For the purposes of this report, Romany Gypsies’ and Irish Travellers’ experiences are reflected in the wider sections specifically focussing on Gypsy and Traveller communities. This does not detract from the protection afforded to Romany Gypsies and Irish Travellers as ethnic groups under the Equality Act and the responsibilities placed upon public bodies.

Background

With more than five million carers across England¹¹, and demographic changes leading to an ageing population, national and local systems must be put in place to ensure that older carers and ageing parent carers are supported to plan for a future when they are less able or unable to care.

Two in three people will become carers at some point in their lives¹². We also know that one in five people in the UK aged 50–64 are carers¹³ and a quarter of all carers are over the age of 65¹⁴. Carers provide the vast majority of care in the UK and are likely to continue doing so in the future.

However, most carers will come to a point where they are unable to care as much as they had been previously or be unable to provide care at all.

⁹There are a number of different groups who fall under the banner of Gypsy and Traveller. These include Romany Gypsies, Irish Travellers, Scottish Gypsies and Travellers, Welsh Gypsies and Travellers, New Travellers, Boaters and Travelling Showpeople. Although only Romany Gypsy and Irish Traveller communities have been established as distinct ethnic groups through case law, Roma communities, Scottish Gypsies and Travellers and Welsh Gypsies and Travellers would meet the same criteria and therefore should be considered as members of protected characteristic groups. While New Travellers, Boaters and Travelling Showpeople are not considered to be ethnic groups, many members of these communities experience similar levels of disadvantage as ethnic Gypsies and Travellers. Many families within New Traveller or Travelling Showpeople communities have been on the road for three or more generations and may one day be considered to be distinct ethnic groups.

¹⁰<https://publications.parliament.uk/pa/cm201719/cmselect/cmwomeq/360/report-summary.html>

¹¹<https://www.england.nhs.uk/commissioning/comm-carers/carer-facts/>

¹²https://www.carersuk.org/images/News__campaigns/CarersRightsDay_Nov19_FINAL.pdf

¹³https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/late_life_uk_factsheet.pdf

¹⁴https://www.carersuk.org/images/Facts_about_Carers_2019.pdf

As a population, we are living longer. As individuals live longer, the likelihood of developing chronic and complex health conditions increases therefore increasing the amount of time an individual could live in poorer health¹⁵. This means more carers will find themselves in the position of having to plan for a future when they may be less able or unable to care. **With the ageing population, there is a latent demand for planning for the future and additional capacity needs to be put in place as early as possible.**

Due to medical advances, disabled people and people with long-term conditions are also living longer. This can mean that families are providing care for a longer timescale than we've seen before. This reinforces the need to plan for a future where the carer is less able to care, put services into place to enable people with care and support needs to fulfil their aspirations and also increases the chances that people with care and support needs themselves become carers – creating co-caring situations.

The impact of caring

There is extensive evidence that caring has an impact on carers' health and wellbeing. Carers' own health and wellbeing needs are often exacerbated or caused by their caring role. Reinforcing findings from NHS Digital's SACE survey¹⁶, NHS England's evidence¹⁷, Carers Trust research¹⁸ and Carers UK research¹⁹, the latest GP Patient Survey (GPPS)²⁰, revealed that:

- 63% of carers reported having a long-term health condition compared with 51% of people not in a caring role.
- Carers are also more likely than those not in a caring role to report problems with mobility and feeling isolated.
- Carers are more likely to be taking five or more medications on a regular basis – 21% of carers reported being in this position, compared to 18% of those not in a caring role.



¹⁵Figure 31 - <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/livinglongerhowourpopulationischangingandwhyitmatters/2018-08-13>

¹⁶<https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-survey-of-adult-carers>

¹⁷<https://www.england.nhs.uk/commissioning/comm-carers/carer-facts/>

¹⁸<https://carers.org/resources/all-resources?type=%2CResearch&p=1>

¹⁹<https://www.carersuk.org/for-professionals/policy/policy-library>

²⁰GP Patient Survey 2019. Results available here: <https://www.gp-patient.co.uk/analysistool?trend=0&nationaldata=1> Carers Trust used GPPS analysis tool to highlight the different experience of carers and those not in a caring role.

Methodology

This project focussed on older carers, those aged over 50 and in particular, ageing parent carer and carers from community groups who face additional barriers to accessing services.

Carers Trust was commissioned by the Department for Health and Social Care to lead this project, working with VCSE organisations in the Health and Wellbeing Alliance. Project partners explored how older and ageing carers can best be supported to plan for these future changes – specifically when they are less able to provide the same level of care or no care at all. These changes might be, for example, age-related or health-related.

All partners reviewed what support (if any) is available for carers who are experiencing a change in circumstances meaning they are less able or unable to care. All partners represent groups that face health inequalities, ensuring the evidence gathered covered groups that are often seldom heard and who face barriers to accessing health and care services.

Focus groups with carers were carried out by Carers Trust; Friends, Families and Travellers; The National LGBT Partnership; and FaithAction to explore what support carers from different communities need/needed to support them in the phase of their caring roles where they are becoming less able or unable to care.

Two surveys were developed and disseminated. One survey was for carers (**202 responses**) while another one collected evidence from service providers (**50 responses**).

Carers UK carried out bespoke analysis of its State of Caring²¹ evidence, highlighting the needs of parent carers over the age of 50.

Carers Trust also held a number of telephone interviews including in-depth conversations with front line practitioners from the charity sector.

²¹http://www.carersuk.org/images/News__campaigns/CUK_State_of_Caring_2019_Report.pdf

Supporting older carers and ageing parent carers to plan for a future when they are **less able or unable to care**

It is clear from existing evidence, the findings of this project and from DHSC's commitment to developing this piece of work, that policies, systems and practices must be put in place to support carers to plan for a future when they are less able or unable to care.

This section sets out the existing evidence about the challenges carers face when planning for the future when they are less able or unable to care.

One of the partners in this project, Sense, part of the Complex Needs Consortium, released a report, *When I'm Gone*, looking at the barriers faced by carers of disabled adults to planning for a future when they were less able or unable to care.

Sense's *When I'm Gone*²² report found:

- 77% of carers have found the process of making decisions about future care and support difficult, as the social care system is difficult to understand and navigate.
- One-third of councils do not know how many disabled people who live in their area rely on friends and family for their care and support²³.



This has an impact on how well councils support disabled people and their families to plan for the future, as well as impacting negatively on the long-term planning of services.

Furthermore, this report found that:

- 41% of family carers surveyed reported that cuts to local services have increased the difficulty of planning for the future,
- Half of the carers (50%) have worries that future funding cuts will limit future options even further than at present; and
- 95% of family carers said they had little or no trust in councils and local services to provide suitable care options for their disabled relative²⁴.

While focussing on a specific group of carers, these challenges resonate with those faced by the majority of carers across the UK. Sense's report highlighted many of the issues faced by carers who are planning for a future when they are unable to care.

²²<https://www.sense.org.uk/support-us/campaigns/when-im-gone/>

²³ibid

²⁴ibid

Sense's report focussed on the carers of disabled adults. It estimates that 1.7 million disabled adults are being cared for by family or friends and there are currently two million carers in England and Wales aged 50-64 and 1.3 million carers aged 60 and over. The report found that 67% of carers surveyed said they have profound fears about what will happen to their relatives when they are no longer able to provide support and 75% of families have not made a plan for what should happen when they are no longer able to provide care.

Good practice example: Carers Network



One good practice example came from Carers Trust Network Partner, Carers Network. Carers Network supports carers in London's Tri-borough area covering Westminster, Hammersmith & Fulham and Kensington & Chelsea.

Carers Network established a project in 2014, through grant funding from a charitable foundation trust. Initially, the project focussed on carers over 65 looking after someone at the end of life. Over time, and as the project was implemented, the scope of the project expanded, and it now serves a broader range of carers.

Through this project, the project manager came into contact with carers who are facing changing circumstances meaning they are becoming less able or unable to care. The project manager then started coordinating support for these carers as part of Carers Network's wider remit to support unpaid carers.

As part of this project and to support carers in changing circumstances, Carers Network successfully applied for a grant from Carers Trust. This grant-funded a series of workshops. The workshops were open to carers of any age but were particularly targeted towards older carers and over half of the attendees were over 65. The future planning workshops covered: Preparing for future care; Making a will; Concessions and benefits; Power of Attorney and Pensions overview.

The project manager highlighted several key conditions which led to the success of the project. These included:

- Establishing what carers in the local area need by talking to carers.
- Engaging with local partners who are now aware of the programme and can refer carers.
- Supporting carers in the day-to-day challenges of being a carer to enable them to plan for the future.
- Relatively small grants to enable them to continue to run the project.
- The commitment of funders to supporting carers in the local area.
- Commitment from senior management within the organisation as well as front line staff.

Wider health, care and support systems

There were some common concerns, and experiences from carers who attended focus groups or completed the survey. These were common across the different groups of carers we focus on and reinforced existing evidence.

The findings from the survey of carers and focus groups with carers reinforced each other, suggesting that carers from across communities, and across England had similar experiences when trying to access support to plan for the future.

As expanded below, carers find the current social care system difficult to navigate, do not have confidence in the quality of care potentially being offered, are being impacted by the lack of available social care, and are not being enabled to plan for the future when they are less able or unable to care because of the day-to-day challenges of being a carer.

The main issues highlighted by carers included:

- A lack of confidence in the social care system as a whole, meaning carers do not seek support.
- The lack of available social care. This leads to many carers picking up more caring responsibilities to the detriment of their own health and wellbeing.
- The majority of carers not being supported to plan for a future when they are less able or unable to care.
- The lack of broader support for carers in the day-to-day challenges they face, making it harder for services and individuals to better plan for the/their future.
- Many carers still not having a Carer's Assessment despite it being their legal right, on appearance of need, under the 2014 Care Act.
- Carers reporting that their own health, ability to care or their age would be likely trigger points when planning for a future when they were less able or unable to care however, the trigger points vary between individual carers.
- A variation in provision of services from providers.

A lack of confidence in the social care system as a whole, meaning carers do not seek support

In different ways, and with different emphasis, carers from across all the focus groups and the carers who completed the survey, expressed concern about the quality and availability of social care for the person with care and support needs, as well as support for themselves as carers.

What carers said

"The future is bleak."

"...[T]hey have washed their hands of us – there is no social care."

"I have never had a Carer's Assessment, even when I have asked for one. The local authority is aiming to cut the number of carers assessments to save money."

"I can't believe how useless it's been. They're fighting not to provide anything and fighting us as they're in deficit so dumping him [the person with care needs] saves money."

What carers said

“There’s been no support ever. When I’ve asked they all say we are not eligible and that’s without an assessment. The system is underfunded and under-resourced and is hugely rationed.”

What carers said

“In the current climate of cuts to support for people with learning disabilities, I am afraid to ask social services for more support in case that leads to a reassessment and support is reduced. There is a sense that it’s best not to raise your head above the parapet.”

One barrier to accessing support was the complexity of the social care system. This was common throughout the focus groups. Carers shared their experiences of trying to navigate the system both for the person they care for and for themselves. Carers often say they find the system complicated and find themselves repeating the same story to numerous professionals. They find that there is a lack of coordination between health and social care and that they as carers are left to coordinate support.

What carers said

“I find it very difficult to navigate a system . . . The [local authority], via a Carer’s Assessment, would have no way of increasing my son’s NHS personal health budget to take into account the cost of managing my son’s staff in the way that my husband and I do. I have no answer, and neither does anyone else. We shall have to live forever! To be honest adult social care was not much better when it came to having a service which managed a team of support staff employed via direct payments. They could only offer a ‘managed service’ which did not provide anything like the same level of supervision and support, which my husband and I provide for our son. We are currently aged 75 and 82, so it probably is about time we could retire!”

What carers said

“I have had to be the driving force in getting care of my daughter and my elderly mother, I don’t have time to do anything else due to the amount of admin/form filling/phone calls.”

Sometimes this lack of knowledge on behalf of the carer could be remedied by simple information sharing by health and care professionals. For example, one focus group participant said they had needed to find a care home for their parent when they were no longer able to care for them. This carer said they were given very little information about care homes in the area which made it difficult for them to find a suitable one. Given that the Care Quality Commission website has ratings for all care homes operating in England, it is disappointing

that the hospital where the person with support needs was staying did not let the carer know about this – leaving the carer without the information they needed.

This experience can also highlight the lack of advice and information being provided by local authorities – despite it being a duty under the Care Act²⁵.

The lack of available social care leads to many carers picking up more caring responsibilities to the detriment of their own health and wellbeing

The more caring responsibilities that carers pick up without the support they need – the more likely it is that carers will ‘burn out’

Across all the focus groups, and the survey, a key theme was that there was a lack of adequate support provided by services, the support that was provided was complex and time-consuming to navigate and the impact caring had on carers’ lives is little understood or acknowledged. Carers felt that professionals did not communicate with each other, so carers had to explain their situation multiple times.

What carers said

“Services are reactive and are aimed at the greatest need, i.e. when you reach crisis. Until you reach that point, there is no support for future planning. And then the choices are dictated by budgets, not personal preference, or even need.”

The majority of carers are not being supported to plan for a future when they are less able or unable to care

Broader support for carers in the day to day challenges they face will enable services and individuals to better plan for the/their future

Another common theme which emerged in the focus groups, which was also brought out in the survey, was that participants had not thought about planning for the future. This was primarily because people felt that they were so focussed on the day-to-day issues of being carers that they either hadn’t considered the future or did not have time to.

This was compounded by a lack of adequate support in planning for the future, with a number of participants never having discussed future planning with any services. Those that had discussed planning for the future felt that they had not received enough advice.

This idea was also reinforced through our expert interviews. Christine Whiley, CEO of Carers’ Resource (Yorkshire and Harrogate), reported that the carers supported by her organisation tell her “we are struggling day-to-day ... we can’t think about the future.”

²⁵<https://www.independentage.org/policy-research/research-reports/information-and-advice-since-care-act-how-are-councils-performing>

The survey results, in large part, reflected what carers said in focus groups. 202 carers aged over 50 completed the survey and the survey found:

- 90% of respondents do not have/did not have specific plans in place in preparation for when they were less able or unable to care.
- The other 10% of carers responding to the survey did have plans in place.



It was evident that carers and services are focussed on the person being cared for which means that carers' needs are not being addressed. This affects future planning as carers were often more focussed on the welfare of the person they were caring for, to the detriment of their own needs or future planning.

Carers' assessments

Across the focus groups and surveys, there was a general distrust or lack of confidence in statutory services and the majority of participants had not had a Carer's Assessment.

Many carers still not having a Carer's Assessment despite it being their legal right under the 2014 Care Act

- 59% had not had a Carer's Assessment since the 2014 Care Act came in.
- 36% had had a Carer's Assessment.
- 5% did not know whether they had had a Carer's Assessment.
- 51% knew they were eligible for another assessment once their circumstances changes.
- 90% had not had an assessment after their circumstances changed.

The survey echoes the findings of Carers Trust's 2016 report, Care Act for Carers: One Year On²⁶, which showed carers were not receiving their statutory assessment and, therefore, had not seen the positive impacts that the Care Act promised.

While statutory carers' assessments are one of the best ways of establishing a carer's needs, we know that many providers go through a less formal assessment of those needs. In these situations, it is still the case that the needs should be recorded and revisited, and that planning for the future should be incorporated in support planning.

Trigger points for support

Participants in the focus group shared what triggered them, or what would trigger them, to plan for a future when they are less able or unable to care. Many carers said that their own health needs (both physical and mental health) would mean that they would be unable to care in the future.

This showed that these trigger points were often different stages of life that impact on someone over an extended period.

Other carers said that their age meant that they would be unable to care in the future. They expressed an awareness that as they grew older, they would be physically unable to provide care, even if their general health remained the same.

²⁶<https://carers.org/resources/all-resources/81-care-act-for-carers-one-year-on>

Other carers said that the condition of the person they care for had developed to the extent that they were unable to continue caring.

In terms of what triggered, or should trigger, support, broadly speaking the survey reflected what was shared in the focus group. When asked: "What led to this support being provided?/Or what will lead to this support being provided?" the survey found:

- 30% said their own health declining.
- 28% said a change in the condition of the person they care for meaning they were less able or unable to care.
- 23% said their own age.
- 21% said becoming physically unable to care.

The survey found that 10% of carers have a plan for the future. These carers were asked what triggered this support for when they are less able or unable to care. Of these carers with plans in place:

- 46% said a change in the condition of the person they care for meaning they were less able or unable to care.
- 38% said their own health declining.
- 38% said their own age.
- 23% said becoming physically unable to care.

Most participants in the focus groups had not been given support to plan for a future when they are less able or unable to care. The support they said they would find beneficial, varied. It included:

- Free or low-cost legal advice and support such as putting into place lasting power of attorney and wills.
- Peer support – including groups from the carers' own community or own identity
- Online support.
- Advice on housing, employment and finances.
- Information about care homes and independent living schemes.
- Support for the day-to-day challenges of being a carer to enable them to plan for the future.
- Support from specialist organisations.

Other family members taking on more caring responsibilities

The focus groups also found that when a carer was becoming less able to care, often another family member would take on more caring responsibilities. While this was true of carers across the four groups we focussed on, it was particularly strong among carers from communities who face additional barriers.

If another family member or friend does become more involved in caring, this could provide an opportunity to support the carer as their circumstances change, and to identify and support the family member becoming a 'new' carer and build up their trust of statutory services.

However, there should be no assumption that another family member or friend will/should become more involved in caring responsibilities. It is vital that caring is a choice, and all carers have control over the care that they provide.

Local authorities reporting that they have a lack of funding for social care²⁷ means a perception may be created that councils have a disincentive to identify and provide long-term support for the person with care and support needs. Across the focus groups and survey of carers, there was certainly a perception that there was a social care crisis and that services were not available.

As highlighted earlier in the findings, carers across the focus groups expressed a lack of confidence in the social care system for the person they care for. This issue must be addressed to ensure that carers have confidence that the social care system can provide the support that the person with care and support needs requires.

It is out of the scope of the report to explore this but the lack of confidence in the social care system seems to stem from carers' experience of the cuts to services, which is linked to the lack of social care funding.²⁸ A long-term, sustainable solution to social care funding is needed if carers are to have confidence in the social care system.

The NHS Health Check²⁹ for people aged over 40 could also be used to identify carers, and if the carer wants to, start conversations and planning for a future when they are less able or unable to care. **For this to happen a question should be added to the Health Check to enable professionals to identify carers.**

The Mid Life MOT³⁰ could play an important role in allowing carers to balance employment and caring responsibilities. Carers over the age of 50 should be encouraged to take a Mid Life MOT by professionals supporting carers to ensure they can get tailored advice on caring, money and employment.

GPs can play a vital role in identifying carers and referring them for support. NHS England has recently released GP Quality Markers to help GPs identify, support and refer carers for specialist support.³¹ Carers Trust worked with NHS England to help develop these.

²⁷<https://www.adass.org.uk/adass-budget-survey-2019>

²⁸<https://www.adass.org.uk/adass-budget-survey-2019>

²⁹<https://www.nhs.uk/conditions/nhs-health-check/>

³⁰<https://www.yourpension.gov.uk/mid-life-mot/>

³¹<https://www.england.nhs.uk/publication/supporting-carers-in-general-practice-a-framework-of-quality-markers/>

Findings from the provider survey including charities and local authorities

There does seem to be some discrepancy between what services said they would or do offer, and what carers perceive to be on offer. Overall, 46% of providers who responded to the survey said they do provide specific support or a specific project for older and ageing parent carers and other groups of ageing carers who are becoming or have become less able to care.

31% of the overall respondents said this was a specified part of a wider carer support contract, while 50% said it is part of a range of support offers they provide while holding the carer support contract locally.

Providers who indicated they did not provide specific support for carers who are planning for a future when they are less able or unable to care, were asked if they were aware of this kind of support being available in their area:

- 60% said No.
- 25% said Yes.
- 15% Did not know.

The provider survey was completed by 50 providers. Of these:

- 90% were from the VCSE.
- 10% from local authorities.

Providers were asked which group if any they were specialised in supporting.

| Group | Percentage |
|--|------------|
| Carers | 76% |
| We do not specialise in any particular group | 16% |
| Gypsy and Traveller Community | 4% |
| Other | 4% |

76% of respondents indicated they are specialist carer support organisations. Of these, when asked if they provided specialised support (for example, in groups specifically dedicated to providing support for particular needs) for any particular community groups, they said:

| Group | Percentage |
|----------------------------|------------|
| Older carers | 43% |
| Parent carers | 27% |
| None | 22% |
| BAME carers | 3% |
| LGBT carers | 6% |
| Gypsy and Traveller carers | 0% |

We asked the provider how they identified carers who need this support. Of providers who said they did deliver this service:

| Trigger | Percentage |
|---|-------------------|
| We offer this as a range of services for the carers we support | 33% |
| Other (Respondents were encouraged to specify 'other' ways and respondents indicated it was a combination of the choices outlined) | 27% |
| Rely on carers self-identifying/self-referral | 22% |
| Part of a 'standard' assessment process | 11% |
| Key trigger points are agreed before and when a carer is approaching these points, front line staff talk to carers | 6% |
| If a carer is in crisis, front line staff consider if they need to plan for the future when they are less able or unable to care | 0% |

Providers were asked what trigger points lead to carers seeking support to plan for the future?

| Trigger | Percentage |
|--|-------------------|
| Carers' own health declining | 88% |
| Carers becoming physically unable to care | 65% |
| The needs of the person with care needs change to the point where carers are unable to continue caring when the carer is aged 50 or over | 52% |
| Carers' age | 47% |
| Retirement and change in their financial situation | 41% |

Experts shared their view that it was often difficult to have conversations about planning for the future with carers. This was because they needed to provide or ensure support for carers for the day-to-day challenges of caring and because it can be emotionally difficult. Carers often do not want to think about a future where they are less able to care – facing their own future in less good health as well as worrying about the support the person they care for will receive.

The hesitance to think about the future, which was reported by the experts interviewed, stemmed from both the widespread reluctance to think about a future with poor health as well as for many carers the lack of confidence in the wider social care system.

One expert, from a specialist carer support organisation, said:

“We run a ‘Caring with Confidence’ course where some of [the conversations about long-term planning are had]. We have conversations about carers accessing respite care – planting the seed in the mind of both the carer and the person in receipt of care that actually the carer may not always be able to provide all the care and actually it can be provided by someone else. Staff sometimes have to] have some difficult conversations with carers, telling them that ultimately it’s about meeting the needs of the person in receipt of care and, if the carer can no longer do this, they will have to look into other options.”



In Yorkshire and Harrogate, the carer support organisation is in the early stages of developing their own tool to help front line staff have these conversations. Reinforcing that these conversations can be particularly difficult for parent carers, Christine Whiley said: “One of the reasons for the tools is because [we need to have these conversations] ... we need to be asking “what happens when you can’t care?” [It is particularly difficult] for parent carers of adult disabled people. They are very anxious about the future ... in the past, we’ve not had anything tangible to help staff.”

Carers assessments are often a good starting point for these conversations – and many carer support organisations do start them at this stage. However, since these conversations tend to be carer-led, and the support provided based on what carers say they need support in, planning for the future is often not brought up proactively by the carer. This is because carers are often focussed on ensuring they have the support they need in the short term.

One expert outlined their process, saying: “When we complete the initial advice assessment (IAA) at the point of Adult carer registration (whatever age or situation) they are asked by a member of the team who completes this process if they have a lasting power of attorney? If the answer is no, they will routinely send them a copy of the Power of Attorney booklet from Age UK.” Other providers use emergency planning projects as a starting point for these conversations. Carers often find it easier to talk about what should happen in a short term crisis where they are unable to care, rather than a longer-term future where they are unable to care.

Good practice example: Oxfordshire Family Support Network (OxFSN)

In July 2016, Oxfordshire Family Support Network (OxFSN) began a three-year project, Embolden, to support, advocate for and empower older family carers aged over 60 who care for a family member with a learning disability. Embolden was funded for this work by Comic Relief over three years; funding officially ended in July 2019, though legacy events occurred in autumn 2019. It was delivered by a I team of three part-time staff³² Embolden was created by OxFSN from the legacy of a previous OxFSN and Comic Relief funded project called Changing Scenes. Both projects focussed on the needs of older family carers, that is over 60 years who supported family members with learning disabilities. One of the outcomes of the project was a Planning for the Future Checklist for Families.³³ This sets out questions covering crisis planning, and longer-term planning as well as asking families questions on the legal and administrative aspects of their caring role.



³²https://www.oxfsn.org.uk/wp-content/uploads/2019/08/Embolden_Evaluation_Report_August_2019.pdf

³³<https://www.oxfsn.org.uk/wp-content/uploads/2017/11/Planning-for-the-Future-Checklist->

Coronavirus and emergency planning

While emergency planning is important, planning for the long-term future is different. It may be one way of opening up that conversation but does not replace the need to plan for the long-term future with the carer and person with care needs.

The Coronavirus emergency highlighted how important it was for carers to have contingency plans in place. Millions of carers needed to stay at home to socially distance themselves or to self-isolate during this crisis. However, we know that this led to carers probably having more caring responsibilities, or being unable to provide the care they usually did, either because they had contracted the virus or had symptoms, and were following Government advice to self-isolate.

The Coronavirus crisis will highlight to many the need for emergency planning. An emergency plan would have helped those carers who had one, assuming local authorities, charities and any health organisations involved had the capacity to implement it.

Conversations about emergency and contingency should be easier to open up now between staff and carers, and this conversation could be the basis for enabling carers to talk about longer-term plans when they are less able or unable to care.

Providers and carers should be given the tools to enable them to have these conversations. Front line staff need to be trained on how to approach the subject sensitively and carers need to be enabled to talk about planning for the future

One expert we spoke to said that their front line staff avoided what could be seen as legal advice. They said: "It's a minefield. Even signposting to local solicitors can be tricky as if they start trying to sell their services to carers and something goes wrong [then we] could be liable."

However, other carer support organisations do not have such fears. This is based on the relationships they have built with local solicitors over the years. They said:

"[Our] staff know that they should not be directly advising carers on these matters, they should always signpost to other organisations. We are fortunate in that we have established good links with trusted local solicitors ... who do not 'give the hard sell' to carers. There is always a staff member in the sessions that are run with local companies such as these so they can be sure that carers aren't being taken advantage of. Staff are clear with carers that they are sharing information with them about what's on offer, and about help and services that may be out there, rather than advising them to take any particular course of action. Staff also signpost them to trusted organisations like Citizens Advice to have these conversations."

Good practice example: Sheffield Carers Centre and Sheffield Mencap & Gateway



Sheffield Carers Centre, a Carers Trust Network Partner, and Sheffield Mencap & Gateway have been working in partnership for many years to ensure that older carers of adults with a learning disability have support. The carers have often been looking after an adult child in the family home for decades and their lives are intertwined. The parents may also have become reliant on their adult child for companionship and support, and the task of planning for a future when the caring role comes to an end feels too daunting, worrying and complex. They also often have concerns about the quality of social care provision. Their adult child may have complex needs that require a combination of housing with packages of support, which requires engagement with a range of organisations to plan and put long-term arrangements in place. Too often, the carer has become too unwell to continue or dies and arrangements have to be made for their adult child in a crisis situation.

The Sharing Caring service is delivered by Sheffield Mencap & Gateway and is part of the overall city-wide Carers Service delivered by Sheffield Carers Centre (SCC). SCC delivers carers need's assessments, support planning and personal budgets for adult carers of adults in Sheffield. The assessment process provides the gateway into a full range of services and support, personalised to the individual needs of each carer. When an older carer of an adult with a learning disability is in contact with SCC, they are referred to the Caring Sharing service for more intensive support, focussed on planning for the future. The Caring Sharing service also refers to SCC where carers have had a long-standing relationship with Sheffield Mencap & Gateway and are already in contact with the service.

The project workers recognise the importance of building trusting relationships as a foundation for having safe conversations about the future with the carers. Home visits are made when the health needs of the carers require it. The staff work with carers on an individual basis to complete person-centred plans, with information about the needs of the adult with a learning disability, and emergency plans. They provide much-needed individual support with navigating the complex world of housing and packages of support for the adult children. There are also group-based activities, including information sessions on topics such as wills and trusts, finances (including welfare benefits) and housing options, and opportunities for social contact with carers in similar situations.

As a result of this service, carers can have difficult discussions in an understanding and supportive environment and take the first steps towards planning for the future with more confidence. Complex situations are made more accessible and less difficult to navigate with the support of the service, which ultimately leads to an adult with a learning disability having their own future secured in a planned and constructive way and a carer having peace of mind, knowing they have made provision for the future of the person they care for.

Older and ageing parent carers and **planning for the future**

Parent carers face many challenges and have often been caring for their child since birth. Sense's When I'm Gone report highlights that parent carers will often provide support such as washing and dressing, as well as practical support such as organising appointments, managing finances and facilitating access to social and employment opportunities³⁴. As Sense points out, "carers provide support day-in and day-out, and year after year, often with limited opportunities to take a break."³⁵

Many of the experts interviewed by Carers Trust also emphasised the challenges that parent carers face and the importance of supporting them. Pauline Kamantas, CEO of Sheffield Carers Centre, and Christine Whiley, CEO of Carers' Resource (Yorkshire and Harrogate), talked about the emotional bond between child and parent, and the impact that possibly decades of caring will have had on parent carers.

One of the experts we interviewed pointed out that: "When services are squeezed it becomes even more difficult. Supported living is very squeezed across the country so carers have to fight to make sure their adult child gets what they need." Adding, "carers have no confidence in the social care system."

Carers assessments

Carers UK carried out an analysis of carers' survey responses in their State of Caring report³⁶. The analysis focussed on older parent carers – defined as those aged over 50 and found that older parent carers are more concerned about the support they expect to receive in the future.

The Care Act gives all carers a right to a Carer's Assessment on the appearance of need. Carers UK's State of Caring report found that older parent carers (71%) were marginally less likely to have had a Carer's Assessment in the last year than 'other groups of carers' (73%).³⁷

Analysis by Carers UK revealed that those that had received a Carer's Assessment were more likely to say that their ability and willingness to care was not properly considered. For those aged over 70, this was particularly the case. These concerns could be because they are especially worried that their own health and wellbeing may be impacting on their ability to care long-term.

A carer's ability and willingness to continue to care should form a key part of their Carer's Assessment under the 2014 Care Act. Not assessing this could be particularly detrimental to carers who might be starting to think about a future when they are less able or unable to care as they may feel an obligation to continue to care, often to the cost of their own health and wellbeing. If plans are already put in place and developed when carers have the time to think about the long term, the change will prove to be less stressful for carers.

³⁴<https://www.sense.org.uk/support-us/campaigns/when-im-gone/>

³⁵<https://www.sense.org.uk/support-us/campaigns/when-im-gone/>

³⁶http://www.carersuk.org/images/News__campaigns/CUK_State_of_Caring_2019_Report.pdf

³⁷ibid

Carers UK's analysis also found that older parent carers (29%) were more likely to feel that their assessment had not properly considered their ability/willingness to care than all carers (21%). Older parent carers (32%) were less likely to say that their assessment had thoroughly considered their ability/willingness to care than all carers (47%), and older carers (37%).

Health and wellbeing

Carers UK's analysis of survey responses from older parent carers to their State of Caring report found that in terms of health and wellbeing, 27% of older parent carers describe their mental health as 'bad' or 'very bad'. This is higher than all carers (26%), all older carers (22%), and older working parent carers (16%). The analysis also found 27% of older parent carers describe their physical health as 'bad' or 'very bad', higher than all carers (22%), older carers (22%) and older working parent carers (14%).³⁸

Juggling work and care

For parent carers who are juggling work and caring, it is vital that planning for the future considers their employment status. Older parent carers (38%) are more likely to be looking after the home/family/dependents full-time than non-parent carers; all carers (33%), and older carers (29%). Older parent carers (21%) are slightly less likely to be retired than non-parent carers; all carers (22%), and older carers (31%).³⁹

Worry about future support

Carers UK's analysis of survey responses from older parent carers to their State of Caring report also highlighted worrying trends in terms of older parent carers being able and enabled to plan for the future. Older parent carers were less confident (6%) than other groups of carers that the practical support they receive will continue in future. This compared to all carers (10%), all older carers (11%), and older working parent carers (8%). Older parent carers (34%) were more likely to say they 'are worried support might be reduced' than non-parent carers. This compared to all carers (24%), and all older carers (23%).⁴⁰

Among different age groups of older parent carers, the age group most likely to say they worry about their own future care needs but haven't done anything about it are those carers aged 65–69.⁴¹ For those worried about their own future care needs but feel they cannot do anything about it, older parent carers aged 50–54 are most likely to say this.

Older parent carers aged over 70 were more likely to say that their ability/willingness to care was not properly considered as part of their assessment than older parent carers under 70.⁴² For most age categories of older parent carers, between one quarter and one-third said that their ability/willingness to care was not properly considered as part of their assessment. 18% of older parent carers had spoken to an NHS professional about what to do if the condition of the person they care for deteriorates/they are no longer able/willing to care for them in the last year. There is little difference across other groups of carers.⁴³

³⁸http://www.carersuk.org/images/News__campaigns/CUK_State_of_Caring_2019_Report.pdf

³⁹Ibid

⁴⁰Ibid

⁴¹Ibid

⁴²Ibid

⁴³Ibid

Good practice example: New Forest Mencap



A report commissioned by New Forest Mencap investigated the support available to parent carers of adults with learning disabilities in the New Forest area. It found that older carers were 'struggling to continue to care'. The report⁴⁴ found that 'transition' to retirement was felt to be a misnomer in the face of continuing responsibilities and duties to care and/or manage care. Carers said that respite breaks are not available so they are unable to take a break and lead the life many other retired people do.

It also found that the Care Act is yet to be applied sufficiently well to make a difference to the lives of people with learning disabilities and/or autism or their carers. Challenges with social service provision including lack of continuity of social worker input, variable and declining levels of expertise, and pejorative attitudes towards carers appear to be worsening. That said, carers are understanding of the pressures on health and social care and are willing to work with them to improve the situation. The report concluded that carers fear for the future as they contemplate who will care for the person they care for once they are no longer able to care for them.

As a result of the findings of the report, New Forest Mencap launched a pilot programme, supported by Lloyds Bank Foundation, in February 2020. The programme aims to identify, reach, connect with, support and signpost 8– 10 parent carers of people with learning disabilities aged over 40, and who live at home in the New Forest District Council area. The programme seeks to understand the barriers in respect of future independent living and enable and support small steps for both parents/carers and people with learning disabilities towards overcoming these.

Over 18 months, New Forest Mencap will work with the local authority, other local agencies and organisations supporting people with learning disabilities to:

- Take referrals to the project.
- Conduct in-depth face to face interviews with up to ten people who fit the scope of the project.
- Create an agreed 'work plan' including smart goals supported by the provision of information, signposting and support. Provide ongoing 'coaching' and support for participants for up to 9–12 months.
- Integrate participants with relevant projects/services 'warm handover'.
- Evaluate the project and host a project sharing event.

By providing a period of sustained support to an individual/family, complex barriers to independent living for adults with learning disabilities who currently live at home can be understood, unpacked and worked through which will reduce pressure on ageing carers. This will enable the process of independent living to be considered and, where appropriate, steps taken to effect changes.

⁴⁴https://www.bath.ac.uk/publications/report-confronting-a-looming-crisis/attachments/RFB_Report.pdf

Carers from communities who face **additional barriers**

Carers from certain communities face additional barriers when accessing health and care services. Alongside parent carers, this project focussed on three communities who are underserved by the wider health and care system:

- Black, Asian and Minority Ethnic (BAME) communities.
- Gypsy and Traveller communities (many of whom are also considered minority ethnic groups).
- Lesbian, Gay, Bisexual and Transgender (LGBT) communities.

Partners on the project explored the barriers that these communities face, what can be done to overcome these barriers and what, if any, specific steps can be taken to make sure carers from these communities are supported to plan for a future when they are less able or unable to care. This report highlights how services can be more inclusive to communities who face additional barriers and where specialist services for these communities might be a more appropriate setting for support.

While the results of the survey and the parent carer focus group highlight that all carers face challenges in securing support in planning for a future when they are less able or unable to care, we know that particular communities face additional barriers. The experiences highlighted below provide an insight into how, from their point of view, each of the communities face challenges when accessing services which are meant to be open to everyone.

Carers from communities who face additional barriers to accessing services also often do not see mainstream services (whether provided by NHS, social care or a VCSE organisation) as “for them”. Many of these carers want and require specialist support.

Not identifying as a carer is a particularly strong theme among communities who face additional barriers to accessing services.

For example, in the focus group with carers from BAME communities, carers did not feel as if they could access support because they didn’t identify as carers. They do not consider themselves to be ‘official’ carers even though a considerable amount of time, effort and emotion are put into looking after the people that they care for.

Many of the focus group participants shared their experience or desire that another family member or friend becomes more involved in caring responsibilities. This was particularly true of participants in the focus groups focussing on BAME and Gypsy and Traveller communities. This is linked to another aspect of the experiences of carers from the BAME and Gypsy and Traveller communities – that they feel it is their “duty” to care for their family members. This is reinforced by a general mistrust of statutory services – particularly from Gypsy and Traveller communities. This mistrust is a result of historical failings, discrimination and previous poor experience of care and support.

Black, Asian and Minority Ethnic (BAME) communities

There is extensive evidence showing that BAME carers face additional barriers to accessing carer support, which is likely to be related to a lack of culturally accessible services. This lack of accessibility is likely to be a result of a mutually reinforcing cycle of the perception of carers from the BAME communities that these services are “not for them”, and services not doing enough to reach out to these communities if people from BAME communities do not access services.

Many BAME communities feel that it is their duty to care for relatives, so this creates another barrier to accessing services as they don't view themselves as 'real carers'. For example, a report by Carers in Derbyshire , which focussed on the experience of BAME carers, found that traditional attitudes can reinforce the belief that everybody has problems to deal with and “you have to look after yourself”, which can make it difficult to ask for help or recognise that help is required. The report also found that some BAME carers can feel alienated from mainstream organisations when workers from that organisation don't participate in community engagement activity or do so sporadically.

Carers UK found that:

- BAME carers face similar challenges to all carers, but also face additional barriers, for instance, cultural barriers, stereotypes and language, which can all increase the chances of poorer health, poverty and social exclusion.
- BAME groups are more likely to be caring for a sick or disabled child, especially for an adult disabled child aged 20– 24.
- BAME carers are more likely to be in poor health compared with White British carers.

A Race Equality Foundation 2018 Better Health Briefing found that:

- The experiences of BAME carers are frequently different to and might be more challenging than those of White carers.
- BAME carers are not only less likely to access services but may also find services less satisfactory than White carers.
- Evidence for the effectiveness of supportive interventions for carers, in general, is disappointing and evidence of their impact specifically on BAME carers is hard to find.

Carers Trust's Care Act for Carers: One Year On report heard in evidence that some BAME carers may not identify with the term 'carer' and that the translation for the word does not exist in Asian languages – therefore the concept does not exist, so it may be hard for a carer to try to explain to the person they support why they need support as a carer. We also heard that some family members or communities may put pressure on a carer to care, rather than seek support with caring. We also heard that we must be wary of saying that carers get support from their community – support may not necessarily be available from a carer's community.⁴⁶

⁴⁶<https://carers.org/resources/all-resources/81-care-act-for-carers-one-year-on>

Carers from BAME communities

The focus group with carers from BAME communities really emphasised how this group of carers feel it is their duty to care for the person they care for, and that it is seen as a family's responsibility. There was a sense that families should "get on with it", reinforced by a general mistrust of statutory services.

For example, one older woman had heart failure and had had a heart bypass operation but keeps on caring for her daughter who has a brain injury. Other carers shared experiences where while they know they are becoming less able to care and will be unable to care soon, letting go of the caring role would prove difficult.

The participants of the focus group shared their experience about one of the best sources of support for them which was a monthly catch up for carers in their area, at the African Caribbean Community Initiative in Wolverhampton. They said it provided them with a lot of emotional support from one another. Another large source of support was from friends and family.

Gypsy and Traveller communities

There is a strong body of evidence showing Gypsy and Traveller communities are underserved by services as a whole. This is also the case for carers from these communities.

Romany Gypsies and Irish Travellers are the ethnic groups most likely to be providing unpaid care in England and Wales and the ethnic groups most likely to provide more than 50 hours of unpaid care per week⁴⁷.

There are specific barriers that carers from the Gypsy and Traveller communities face. Friends, Families and Travellers analysis shows:

- Many Gypsy and Traveller carers would not identify themselves as 'carers' and may not be aware that they can receive support.
- Many Gypsy and Traveller carers will not attempt to access support if they do not feel the service being offered is culturally appropriate.
- For Gypsies and Travellers, community isolation was identified as a barrier for those who have experienced long-term misunderstanding and prejudice. This leads to people feeling increasingly distant – both geographically distant from services as well as the feeling that services do not understand their needs – from services, including health services. It is not uncommon for Gypsies and Travellers to travel hundreds of miles to see a known GP or trusted support worker, rather than risk rejection at a local surgery or office⁴⁸.

⁴⁷<https://www.ons.gov.uk/>

⁴⁸<https://www.mecopp.org.uk/mecopp-publications/2019/1/9/hidden-carers-unheard-voices?rq=hidden%20carers>

As a whole, Gypsies and Travellers are the ethnic groups most likely to experience poor health, but within these communities, those who provide 50 hours or more of unpaid care per week are almost twice as likely to be in poor health compared with those in the same ethnic group providing no unpaid care.⁴⁹ Of those who said in the 2011 Census that they were carers from the Gypsy and Traveller communities, only 46% said that they were living in good health.⁵⁰

There are a number of significant barriers to accessing care services including:

- Failure of health services to accept patients and carers who are travelling and therefore have no fixed address.⁵¹
- Failure of services to communicate in an accessible way (45% of Friends, Families and Travellers' service users have low or no literacy), which contributes to notable barriers to care services and access to welfare benefits.
- Digital exclusion (of 50 people surveyed across the UK from Gypsy and Traveller communities, one in five Gypsy and Traveller participants had never used the internet, compared to one in ten members of the general population).
- Lack of awareness around the concept of carers and a lack of trust in mainstream services, as a result of previous experiences of discrimination.⁵²

One focus group participant stated: "If a stranger has to step in, they wouldn't know our ways or my son's specific needs."

Another participant stated: "We would rather do it ourselves; what's the qualification of the [care worker]? [We] don't want to hand over to that."

One focus group participant said there was little understanding of the importance of family among the Gypsy and Traveller communities in care settings which meant they felt care home staff got "annoyed" with the number of visitors Gypsy and Traveller residents may have.

⁴⁹<http://webarchive.nationalarchives.gov.uk/20160105204901/http://www.ons.gov.uk/ons/rel/census/2011-census-analysis/ethnic-variations-in-general-health-and-unpaid-care-provision/sty-trends-in-health.html>

⁵⁰<https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/articles/whatdoesthe2011censustellusaboutthecharacteristicsofgypsyoririshtravellersinenglandandwales/2014-01-21#health-and-related-characteristics>

⁵¹<https://www.gypsy-traveller.org/wp-content/uploads/2019/03/No-room-at-the-inn-findings-from-mystery-shopping-GP-practices.pdf>

⁵²<https://www.gypsy-traveller.org/wp-content/uploads/2018/09/Digital-Inclusion-in-Gypsy-and-Traveller-communities-FINAL-1.pdf>

The focus group with carers from Gypsy and Traveller communities highlighted the need for service providers to do more to overcome barriers to services faced by Gypsy and Traveller communities. The onus must be placed on providers of statutory services to be open to all sections of their population.

Participants in this focus group said the only support they received had been through Friends, Families and Travellers.

None of the participants in the focus group for carers from Gypsy and Traveller communities had been offered a Carer's Assessment or were aware of their entitlements under the Care Act (2014). Despite this, none of the participants wanted social care involvement due to past experiences and fear of discrimination. Further to this, many people had not considered accessing support for their caring role because they felt this was simply a normal part of their lives: "We don't think of ourselves as carers, we just get on".

One participant highlighted that the failure of services to offer accessible information can be a barrier to accessing support for people with low literacy levels. 45% of Friends, Families and Travellers' beneficiaries have low or no literacy, and this is one of the reasons specialist support from Friends, Families and Travellers can be crucial. Outreach workers from Friends, Families and Travellers understand the needs and preferences of the individuals they work with and can help with reading and filling out forms and explaining written information.

The focus group with carers from the Gypsy and Traveller communities highlighted a mistrust of statutory services. All participants in this group stated that they had a very high level of concern about having any involvement with social care; people would simply avoid any support that social services could provide due to anxiety around, and practical experiences of, discriminatory practice and attitudes.

In the focus group for carers from the Gypsy and Traveller communities, all participants stated that they would not feel comfortable having a stranger provide care to their family members.

Lesbian, Gay, Bisexual and Transgender (LGBT) communities

There is extensive literature to suggest that LGBT people face a number of barriers to accessing health and social care, including encountering discrimination and service providers lacking awareness of how to provide high-quality support to LGBT people. This can increase reluctance to access support, which may potentially mean that LGBT carers are less likely to access support for future planning or that the support they do access does not best address their needs.

LGBT people are more likely to be reluctant to access mainstream support often due to a fear of facing discrimination and/or previous negative experiences.^{53 54} Health and social care professionals can be discriminatory and often lack understanding around what good personalised care for LGBT people looks like.^{55 56}

LGBT people over 50 are more likely to be socially isolated and estranged from their family.⁵⁷ This can mean that LGBT carers may not be getting adequate support from those around them. This also means public services might be even more important for many in LGBT communities.

Furthermore, LGBT carers may also be caring for an LGBT person, creating further concerns around planning for the future, for example, concerns that a care home or a paid care support worker may not be respectful of their LGBT identity.^{58 59} There is a range of evidence to suggest that LGBT people have a number of specific concerns related to receiving care. A 2011 Stonewall survey found that three in five older LGB people were not confident that social care and support services, like paid care support workers or housing services, would be able to understand and meet their needs. More than two in five had the same concerns about mental health services and one in six about their GP and other health services.⁶⁰

If LGBT relationships are not recognised in the same way as heterosexual relationships, there will be problems when planning for the future. This creates problems with future planning as someone's partner or friends may not be recognised as their next of kin despite the fact that they may be considered by someone to be their 'chosen family'.

Chosen family in LGBT communities is a phenomenon where LGBT people 'prioritise and value the opinions and relationships of friends over their blood relatives. These friends replace their

⁵³https://www.stonewall.org.uk/system/files/lgbt_in_britain_health.pdf

⁵⁴https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/721704/LGBT-survey-research-report.pdf

⁵⁵https://www.stonewall.org.uk/sites/default/files/unhealthy_attitudes.pdf

⁵⁶<https://s3-eu-west-1.amazonaws.com/lgbt-media/Files/f7a0343c-67ee-4777-8882-739a44d41a70/LGBT%2520FOUNDATION%25202016-17%2520Primary%2520Care%2520Survey%2520Report.pdf>

⁵⁷https://www.stonewall.org.uk/system/files/LGB_people_in_Later_Life__2011_.pdf

⁵⁸https://www.stonewall.org.uk/system/files/LGB_people_in_Later_Life__2011_.pdf

⁵⁹https://secure.manchester.gov.uk/downloads/download/6603/research_study_into_the_trans_population_of_manchester

⁶⁰<https://www.stonewall.org.uk/resources/lesbian-gay-and-bisexual-people-later-life-2011>

blood family and become their chosen family. This occurs for a variety of reasons, but mainly because the LGBT person does not feel adequate support and acceptance from their blood relatives, especially parents, and is forced to turn to the people from whom they do receive that support.⁶¹

A lack of recognition of chosen families may create conflict over who is involved in future planning. This may lead to LGBT carers feeling invalidated and excluded.

Carers from LGBT communities

The most common and significant issues that were brought up in the focus group with carers from LGBT communities were unrelated to people's LGBT identities, however, there were still a few issues that were raised that need to be recognised and addressed.

A participant spoke of not accessing support groups and services as they were concerned that they might face homophobia. They also said that they could not relate to participants at support groups they had previously attended because there were no other LGBT members and they felt it was difficult to build up the connections they were seeking from the group.

A number of participants described experiences where health and care staff assumed they were heterosexual. This was described as a "minor irritation" by one participant, while another said that this sort of experience made them reluctant to engage with the service again. A participant said that they had people in their social circles telling them that coming out as non-heterosexual had negatively impacted the person they were caring for, which was upsetting to the carer.

It was also felt that staff often did not understand the concept of "chosen families" within LGBT communities. Carers felt this often meant that staff don't know how to deal with LGBT relationships and people as they don't 'fit the system'. They also said there was a lack of knowledge and understanding by professionals of the legal rights for LGBT relationships.

⁶¹https://wiki.ubc.ca/The_Phenomenon_of_Chosen_Family_in_the_LGBT_Community_2

What a pathway could look like

Once a carer is identified and referred for support for their caring role, the pathway to supporting them plan for the future could follow the below path:

The carer is identified and referred for support in their caring role

- Support is put in place to support carer in the day to day challenges.



As part of support – trigger points for longer term planning are identified by carer and frontline providers

- Providers should talk to carers about why these trigger points are being identified, and why long term planning is important.
- The carer is asked if they would like support from other organisations once which might specialise in supporting people and carers from the community the carer identifies



Further conversations and reassessments happen to make sure carer needs are documented

- These can be formal statutory reassessments under the Care Act, or more informal assessments carried out by providers.
- The important outcome is that providers are keeping track of carer needs and wishes.



Once trigger points are approaching – planning begins

- Conversations with carers.
- Conversations with the person or people with support needs.
- Conversations with other family members.



Create a support plan

- Create an action plan relating to the specific needs and wishes of the carer, person with support needs, and other family members who have been involved.
- Outline what the actions are and how – and by who – the support is going to be put in place.
- Working with other organisations, a support plan is put in place to ensure carers get the support they need.
- Include any referrals to other organisations that will take place and a lead contact.



Store, record and revisit if necessary

- As this plan will be put in place ideally before it is needed, keep it as a 'live' document.
- Revisit it periodically to ensure it is up to date and still in line with everyone's wishes.
- Share information in line with confidentiality rules.

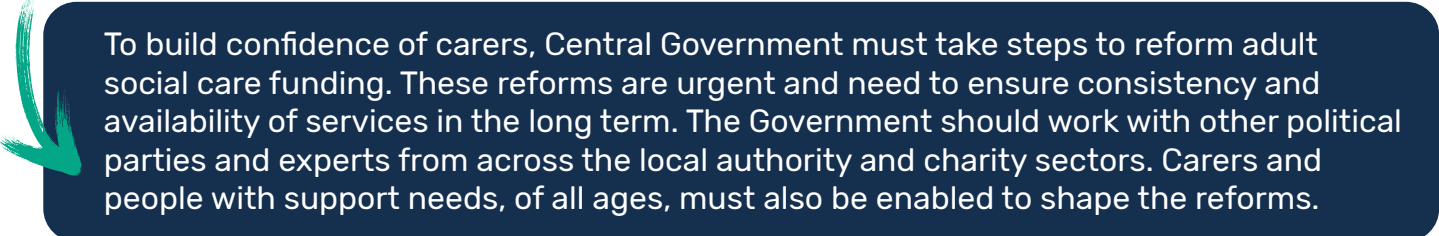
Recommendations and actions needed

1. Adult social care needs sufficient and sustainable funding.

Social care funding must be sufficient and sustainable. This funding must ensure that everyone with care and support needs – whatever their age – has the support they need. The social care system must also ensure carers are identified and get the support they need at the time they need it. Support for carers must also include support for them to plan for a future when they are less able to care.

The ADASS Budget Survey showed that many Directors of Adult Social Care Services do not have confidence that they have the funding to fulfil their duties under the Care Act⁶². Central government must ensure that local authorities have the funding they need. Statutory Carer's Assessments are essential and it is clear that not all carers are receiving them. This must be remedied if government and commissioners want to support unpaid carers.

Carers' experiences of the lack of services available to the people they care for, as well as for them as carers, feeds into the lack of confidence many carers report.



To build confidence of carers, Central Government must take steps to reform adult social care funding. These reforms are urgent and need to ensure consistency and availability of services in the long term. The Government should work with other political parties and experts from across the local authority and charity sectors. Carers and people with support needs, of all ages, must also be enabled to shape the reforms.


2. Early identification of carers and their support needs are still vital. Without this, subsequent support to plan for a future when carers are less able or unable to care becomes more difficult.

3. To identify carers who need support to plan for a future when they are less able to care, more needs to be done to identify all carers and provide carers with the tailored support they need.

The focus groups and surveys both highlighted how important early identification and support are for carers from all groups. The 2014 Care Act is in its fifth year of implementation and yet we still find that carers are not being identified, are not getting a Carer's Assessment, and often this leads to carers not getting the support they need.

This is often exacerbated by a lack of availability of support both for the carer and for the person with care and support needs. The focus groups and survey both found that carers find the social care system complicated, are unable to access support and do not feel the statutory bodies will be able to support them or the person they care for.

⁶²<https://www.adass.org.uk/adass-budget-survey-2019>




Central Government, local authorities, health and social care partners and the VCSE must continue to work together to ensure carers are identified and supported. Local authorities, health services including GPs, care services and charities should use all tools available to them to ensure they are identifying carers as early as possible. Local authorities should ensure they are complying with all aspects of the 2014 Care Act including duties around advice and information, prevention and availability of support. Providers should use tools, including the resources attached to this report, to ensure they are supporting carers to plan for a future when they are less able or unable to care.

4. Carers are entitled to a Carer's Assessment under the Care Act. This statutory assessment is meant to consider all a carer's support needs as a carer, and prevent further needs from developing. The Carer's Assessment could provide the right opportunity to start conversations about planning for the future with the carer.

Notwithstanding the financial difficulties they face, local authorities should be identifying carers and ensuring they have a Carer's Assessment. To enable this to happen, local authorities should work in close partnership with health and care providers and charities.

Whoever provides the Carer's Assessment should be aware of the need to ask carers about planning for the future.



Services which provide carers assessments should use the resources attached to this report to identify carers who need to plan for the future and use the resources to enable them to do so. The Carer's Assessment is one route towards doing that, but providers must remain aware of other opportunities to have these conversations.


5. Support for carers to plan for a future when they are less able or unable to care needs to be recognised as an important area for development for future services to consider.

The number of carers, demographic changes and the fact that we are living longer with an increased chance of developing chronic and complex health conditions⁶³, all mean that support for carers to plan for a future when they are less able or unable to care, should be considered a vital part of development for future services to deliver.

It is important that Central Government recognises this and makes necessary long-term reforms while putting sustained funding into adult social care to ensure high quality services. Local authorities should also recognise this and commission services that will ensure carers in their area have access to this support. Finally, providers should work together with other local organisations, as well as commissioners, to ensure they are delivering this service.

It is also vital that issues around the quality and availability of social care for people with care and support needs are addressed. Carers and the people they care for need to know that good quality social care will be available to the person with care and support needs.

⁶³Figure 31 <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/livinglongerhowourpopulationischangingandwhyitmatters/2018-08-13>



Local authorities should take steps to ensure carers are supported to plan for a future when they are less able or unable to care. This could be achieved through ensuring carer support contracts have a specific requirement for providers to do so. Contracts should encourage long term support for carers and not just outputs based on the number of carers supported. Carers must get the support they need at the time they need it.

6. Once a carer is identified, the support plan that is developed for the carer should set out trigger points that may mean a person is less able or unable to provide care.

As part of the support plan that is developed to support carers, trigger points should be identified. Steps should be taken early to identify when a carer might be less able or unable to provide care and measures put in place to support and enable this. These trigger points should be understood as changes in a carer's life which mean they are less able or unable to care. The impact of these changes is likely to be gradual which increases the importance of early dialogue and regular conversations with carers about these different stages of a carer's journey.

The trigger points for support will include but are not limited to:


- A change in the condition of the person they care for meaning carers are less able or unable to care.
- Carers' own health declining.
- Carers' own age.
- Carers becoming physically unable to care.

These trigger points may be interlinked. Providers should have this information, so it should be possible to set out plans for when carers are approaching these points in their lives. Providers should also proactively and regularly check in with carers about their ability to continue caring, rather than being reactive and waiting for carers to raise it.

These trigger points for support, or stages in a carer's journey, may take years to develop so steps must be taken early to identify these trigger points and action taken to allow for long-term planning. While these are the main trigger points, other potential trigger points will need to be taken into account, such as finances, housing, other caring responsibilities, or a change in employment status. Providers must take into account how all these different trigger points interact with each other.

Planning for the future is a preventative measure. Plans and actions should be taken as early as possible to ensure that when circumstances do change – carers and people with care and support needs know what will happen.

There is a complex interplay between all of these other potential trigger points that can impact on a carer's ability to plan, a carer's choices and the support they need. That is why services need to be aware of the necessity to plan for the future and work with carers to do so. The earlier conversations about planning for the future occur, the more likely it is that positive interventions can take place.




Providers and front line staff should use the resources attached to this report to work with carers, and people with support needs, to ensure carers can plan for a future when they are less able or unable to care. Front line staff providing care and support must be provided with training on how to have these conversations with carers and should work closely with partners from across sectors to ensure carers get the support they need.

7. Subsequent Carers' Assessments should revisit these trigger points.

From the focus groups and surveys, we also know that carers are not getting assessments when their circumstances change. The support that carers receive should be revisited regularly – through formal, statutory re-assessments and regular conversations with carers about their support needs.


All trigger points highlighted above should form the basis of the conversations. These trigger points normally represent changes in a carer's life and caring journey and will have an impact over time – rather than an immediate change. If trigger points are identified early, it will be easier for providers to put measures into place that support carers who are becoming or have become, less able or unable to care.



Providers of Carers' Assessments should be in regular contact with carers to ensure their circumstances have not changed significantly as well as offering regular subsequent re-assessments.

8. Organisations across the statutory and voluntary sector must work together to ensure carers get the support they need at this stage of their caring journey.

Partnership working on a local and national level is vital in ensuring carers get the support they need at the time they need it. To ensure that carers get the support they need at this stage of the caring journeys, all organisations in the local area must work in partnership. That includes partnership working between statutory organisations, between charities and across sectors.



Statutory and charity organisations should use all the tools available to them to build strong and viable partnerships.


9. The NHS Health Check and Mid Life MOT should be used to enable carers to plan for the future.

The NHS Health Check for people aged over 40 could also be used to identify carers, and if the carer wants to, start conversations and planning for a future when they are less able or unable to care. For this to happen a question should be added to the Health Check to enable professionals to identify carers.

The Mid Life MOT could play an important role in allowing carers to balance employment and caring responsibilities. Carers over the age of 50 should be encouraged to take a Mid Life MOT by professionals supporting carers to ensure they can get tailored advice on caring, money and employment.

GPs can play a vital role in identifying carers and referring them for support. NHS England has recently released GP Quality Markers to help GPs identify, support and refer carers for specialist support.⁶⁴

⁶⁴<https://www.england.nhs.uk/publication/supporting-carers-in-general-practice-a-framework-of-quality-markers/>



NHS England should add questions about being a carer to the mandatory questions list for the NHS Health Check.

Providers and front line staff should be aware of the Mid Life MOT and encourage carers who are over 50 to complete it. Front line staff may complete the MOT with the carer to ensure conversations about planning for the future happen.


10. Planning must take carers' individual needs and circumstances into account.

Often this planning will involve another member of the family taking on more, or all of the caring responsibilities. If this is the case that carer must be identified and supported for their own needs.

When carers become less able or unable to care, other family members or a friend may take on more or all of the caring responsibilities. In the case of parent carers, this may be that a sibling of the person with care and support needs starts to take a more active caring role. In the case of someone looking after their spouse, it may be one or several of the adult children who become carers.

While no presumption should be made that another family member will provide care, we know the reality is this often happens.

Sometimes there is a conversation between family members which means family members are fully aware of what is happening. Sometimes, like many other caring roles, this is more gradual or piecemeal with an individual taking more caring responsibilities on overtime meaning the caring role is not immediately recognised.




Providers and front line staff have a role in facilitating these conversations between families. If family members are taking on more caring responsibilities, then they should be identified as a carer, and receive a Carer's Assessment and the support they need.

11. The views, needs and aspirations of the person or people with care and support needs must also be jointly included in this planning, combined with carers' voices as expert partners in care.

Conversations about planning for the future when a carer is less able or unable to care should involve professionals, carers and people with support needs. This will ensure that long-term planning can work towards both enabling the carer to take a step back from caring and achieve what the person with care and support needs want to achieve.

These conversations need to be handled sensitively. A whole family approach will take into account the views and needs of everyone involved. Sometimes conversations will need to happen separately to allow all parties to express their views openly. Any disagreements between the carer and the person with care needs should be handled sensitively by front line staff.



Service providers and front line staff should talk to carers and people with care needs when developing plans. Planning and conversations about carers becoming less able or unable to care should also include the person with care and support needs. The views, needs and aspirations of the person with care and support needs must be considered alongside carers' voices as expert partners in care.


12. If the caring role is not being taken on by another friend or family member – steps must be taken to ensure suitable and adequate statutory support is in place.

When a carer becomes less able or unable to care, the person with care and support needs may need more support from external providers, including a move into residential care, supported accommodation or independent living.

If this is the case, carers need to feel that they can have confidence in the availability and quality of social care. An issue that was highlighted in both the focus group and survey was that carers do not have confidence in the social care system.

We know that a major source of this lack of confidence is the lack of funding. While outside the scope of this report, a lack of long-term sustainable social care funding remains a major obstacle to carers and the people they care for getting the support they need.

No assumption should be made about another family member taking on the caring role. Future planning must also take into account the aspirations of the person with care and support needs.



Central Government must ensure social care is reformed to ensure that people with care and support needs have access to the support they need.

13. Some communities which face additional barriers may prefer support from specialist organisations.

The focus groups with communities that face additional barriers to accessing services underlined the need for specialist support.

The focus group with carers from the Gypsy and Traveller communities emphasised the invaluable support provided by specialist organisations. This included support in ensuring that carers from these communities were able to fully engage with the information provided to them. It also relied on carers from these communities having more trust in specialist organisations rather than mainstream provisions.

This was also the case for carers from the BAME communities. For carers from these communities, peer support from other carers from the same community was important as they shared the same or similar cultural expectations. Being able to share their experiences with peers who have had similar experiences within the same community can be valuable for carers.

Carers from LGBT communities also face barriers to accessing services. For many carers from these communities, previous experiences meant they were often hesitant to access 'mainstream' services and felt these services may not consider their needs as people from LGBT communities.

Commissioners and provider should ensure services are available to support communities who face additional barriers. This specialist support could be provided through partnership working and co-design on the local level. Service providers must be able to refer carers for support to other local organisations who may be able to provide that specialist support.

14. All services should be open to all members of the community.

'Mainstream' services must be open, accessible and serve all communities. In addition, mainstream services should be reminded to fulfil their responsibilities under the Public Sector Equality Duty, including to:

- Eliminate unlawful discrimination.
- Advance equality of opportunity between people who share a protected characteristic and those who don't.
- Foster or encourage good relations between people who share a protected characteristic and those who don't.

Local services must engage with communities who face additional barriers, to build up trust that is missing, design services that respond to needs and to ensure they are compliant with the Accessible Information Standard⁶⁵.

15. Carers want to be involved in the design of support services.

The principle of co-design should be at the heart of local service delivery. Carers from across all communities should be enabled to design services which provide the support they need. This requires early engagement from commissioners, services providers and other local partners.

Co-design should ensure the services that are developed, commissioned and provided reflect the needs of service users. Co-design also requires local partners to work together, co-operating to ensure that the individual strengths of partners are brought to service delivery.

Commissioners and providers should work together and with all service users to ensure services meet their needs. There are tools from across the statutory and charity sector that set out good practice in co-design and these should be used to ensure local communities can shape local services.

⁶⁵<https://www.england.nhs.uk/ourwork/accessibleinfo/>

Next steps

Accompanying resources

Alongside this report, there are resources for commissioners, providers and front line staff, to help in the development of support for carers to plan for a future when they are less able or unable to care. Also included are resources that providers and front line staff can share with carers to encourage them to think about planning for the future, and to support carers in doing so.

Further research

The below are all areas and issues touched upon during this work that need further research.

1. How the impact of funding cuts to the voluntary sector has impacted on the ability of 'mainstream services' to work alongside specialist support services to make sure services are open to all.

The resources should encourage service providers to make provision to ensure their services are accessible to a wide range of communities. Further research should look at whether funding cuts have squeezed out smaller, specialist organisations, and what impact this has had on service users who might want specialist support.

2. Support for carers to plan for a future when they are less able or unable to care when they care for someone with mental health issues.

Caring for someone with a mental health issue may not require as much physical caring as caring for someone with other conditions. It is, therefore less likely that carers' own physical health would directly trigger them being less able or becoming unable to care. More specific research needs to be done into whether carers of people with mental health issues require different support.

3. The mental health of carers who become less able or unable to care.

Being a carer often becomes an identity for the carer. They may have been caring for decades and the loss of that identity may have an impact on their mental health. While there is research on support for bereaved carers, more research may be needed into this and how to support former carers of people with care and support needs who are still alive.

4. The implementation of the 2014 Care Act.

Five years after its implementation, feedback from carers suggests that the Care Act is still not being implemented in full. We know that funding is a major reason for this, with local authorities having to make decisions on where to spend their limited resources. However, the Care Act is a crucial step forward in carers' rights and should be given the funding it needs to fulfil its potential.

5. Co-caring and people with support needs becoming carers.

The issue of co-caring and/or people with support needs becoming carers to their ageing parents was raised by several experts. As the population as a whole grows older, situations whereby the person with care and support needs becomes a carer themselves will become more common. This was particularly raised in the context of adults with learning disabilities but could be equally applied to people with other support needs.

About Carers Trust

Carers Trust is a major charity for, with and about carers. We work to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

We do this with a UK wide network of quality assured independent partners and through the provision of grants to help carers get the extra help they need to live their own lives. With these locally based Network Partners we are able to support carers in their homes through the provision of replacement care, and in the community with information, advice, emotional support, hands on practical help and access to much needed breaks. We offer specialist services for carers of people of all ages and conditions and a range of individually tailored support and group activities.

Our vision is that unpaid carers count and can access the help they need to live their lives.

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Prepared for: The Department of Health and Social Care and the VCSE Health and Wellbeing Alliance

We would like to thank the many people who have been involved in this project:

- The carers who generously gave up their time to be part of the focus groups or complete the survey.
- The staff and practitioners who shared their experiences of providing support.
- The Carers Trust team including Ramzi Suleiman and Laura Bennett.
- All our HW Alliance partners including Josie Garrett (Friends, Families and Travellers), Jenny Hadgraft (FaithAction) and Sophie Meagher (National LGB&T Partnership).
- Our colleagues at the Department of Health and Social Care.

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