

Strategic Vision for Carers in Buckinghamshire

Commissioning Strategy 2016 - 2019

Buckinghamshire County Council
Aylesbury Vale Clinical Commissioning Group
Chiltern Clinical Commissioning Group



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Executive Summary

The contribution of informal carers to the health and wellbeing of our general population is immeasurable.

Over the next five years 10.6 million people will take on a new caring role for a disabled, older or seriously ill relative or friend. *Carers*

Caring is something that, increasingly, affects us all at some point in our lives, whether we find ourselves looking after someone we love, or we need some support ourselves.

However, caring without enough support in place can have a huge impact and it is taking its toll on millions of families throughout the UK. Whether caring is full-time, or it is part of a stressful mix of work and other family responsibilities, many carers find they don't have the time or energy to maintain relationships, stay in work, or look after their own health and wellbeing.

It is absolutely vital that their contribution is recognised, supported and valued by the local authority, health and other statutory agencies. Caring is an issue which could affect us all at some point in our lives.

We may need care ourselves, or may choose to provide care for a friend or loved one. The assistance provided by carers cannot be overestimated and it is thanks to their dedication that many people they care for in Buckinghamshire are able to retain their independence and continue to live in their local community.

We do not need to change carers' hearts and minds because they are acutely aware of what caring means. However, we do need to change how services and support are planned and delivered and take forward action which will benefit carers now and in the future. This strategy, together with other policies, will seek to achieve this.

The census and other surveys indicate that there may be around 5,981 such carers in Buckinghamshire, and some of these are young adult carers, but all of them are facing difficult challenges in their everyday lives.

Caring is often rewarding but can also be very demanding, with carers devoting large parts of their own lives to the lives of others. The valuable role that carers play in our society must not go unrecognised.

Given the evidence about demographic and social changes, and the pivotal role of carers in sustaining care in the community, Buckinghamshire County Council and the Clinical Commissioning Groups (Aylesbury Vale and Chiltern) are expected to have regard to the key messages in this strategy and to implement the key action points as local priorities dictate.

This strategy will aim to improve the quality of life for carers and their families in Buckinghamshire.

Why we need a Carers strategy

- 1.1 This strategy has been developed in direct response to the Government's 'Next Steps for National Carers Strategy 2010', which was refreshed in 2014, and the NHS 'Priorities for Carers' issued in 2014 alongside recommendations made following a comprehensive needs analysis and engagement with carers, voluntary groups and statutory bodies in Buckinghamshire carried out by Adult Social Care and Public Health in early 2015.
- 1.2 The strategy sets out what we have been doing and a vision of what still needs to be done to give carers the quality of life we believe they deserve, including the basic rights of carers to accessible information, employment and training opportunities and stronger support networks.
- 1.3 The strategy relates to **adult carers** (aged 18 +) and **young adult carers** (16 – 25), who care for an adult living in Buckinghamshire. An adult carer who cares for someone living outside of Buckinghamshire will need to refer to the relevant local authority where the cared-for is living.
- 1.4 The strategy aims to address in a practical way the support that carers want and need to allow them to continue caring, and to give them as much access as possible to the same opportunities that those not in a caring role can enjoy. The actions proposed within the strategy will make a real and valued difference to the range and quality of services provided to carers.
- 1.5 Although not every aspect can be realised overnight the strategy represents a firm commitment from Buckinghamshire County Council (BCC) and the Clinical Commissioning Groups (CCGs), who recognise that carers are vital contributors to our communities deserving our full support and encouragement, and that will be fully integrated into our existing priorities and plans.

Who carers are and what they do

- 1.6 The 'National Carers Strategy' states that: "A carer spends a significant proportion of their life providing unpaid support to family and potentially friends. This could be caring for a relative, partner, friend or neighbour who is ill, frail, disabled or has a mental health problem or substance misuse problems".

- 1.7 Carers can be adults caring for other adults, parents caring for ill or disabled adults/children or young people who care for another family member. Caring is an issue that can affect us all at any time irrespective of job or status and every caring situation is unique.
- 1.8 Many carers would not identify with the term 'carer', rather seeing themselves as dutiful parents, sons, daughters, partners or friends accepting and discharging a responsibility toward a friend or loved one. Therefore, the use of the term carer must be carefully considered.
- 1.9 It is important that carers are not confused with paid workers, who are sometimes called carers too. A 'care worker' or 'care staff' are either undertaking a caring role as part of paid employment or as volunteers attached to a voluntary organisation. Equally, carers are not volunteers. There may well be volunteers supporting the cared-for person and/or the carer, but they are not the carer.
- 1.10 Carers under the age of 18 are defined as **young carers** and they usually care for siblings or parents. **Parent carers** care for children with special educational needs and disabilities. **Older carers** over the age of 60 may face added difficulties due to financial constraints and the carer's own health needs. **Condition Specific carers** are classified by the needs of the cared-for. For example: dementia carers, mental health carers, substance misuse carers, learning disability carers, carers of those with other serious or life-limiting conditions.
- 1.11 Sometimes the cared-for person will have more than one condition. Some carers care intensively or are life-long carers. Others care for shorter periods. The carer does not need to be living with the cared-for person to be a carer. Anybody may become a carer at any time, sometimes for more than one person.
- 1.12 Carers are now, and will remain, fundamental to strong families and partnerships, and to resilient and cohesive communities. The lives of carers and the cared-for are closely intertwined, but they are not the same.

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Who this strategy is for

- 1.13 This strategy will be of interest to those who can improve the lives of carers and who can influence the support provided to carers. It is for decision-makers, commissioning managers and practitioners, especially within Buckinghamshire County Council, the Clinical Commissioning Groups, Carers Partnership Board, Health & Wellbeing Board and all statutory agencies and voluntary organisations involved in supporting carers.
- 1.14 Services that support mainly young carers will be interested in the Children's Strategy. Although there are important distinctions to be drawn between young carers and adult carers, there are also similarities in the caring experiences. Additionally there are important transition issues, especially with regard to support for young adult carers, whom we cover in this strategy. This strategy does not attempt to address the issues facing young carers.
- 1.15 The strategy will also be of interest to the carers themselves to understand what statutory bodies and voluntary organisations will do to support carers over the next three years in Buckinghamshire.

The value of carers in health and social care

- 2.1 We do not need to understand each individual's circumstances or motivation in what is often a very personal and private activity, but we do need to recognise the existence and the value of carers, both to the person they care for and to the wider community.
- 2.2 It is clear that carers enable many thousands of vulnerable people who need support to continue to lead independent lives in their local communities. At the same time carers reduce the amount of input that health and social services, and other agencies, might otherwise have to make. It is important that we act positively to protect the interests of carers and to foster a climate where they can continue to care for as long as they wish, and are able to do so without jeopardising their own health and wellbeing, financial security, or expectations of a reasonable quality of life.
- 2.3 We want to enable carers to make more choices for themselves and to have more control over their lives. We want services to recognise carers as individuals in their own right.
- 2.4 It is expected that in the future there will be an increasing demand for care largely due to the fact that people are living longer, resulting in a growth in the numbers of older and more frail people with complex needs living in the community. In addition many people, for example individuals with learning difficulties or dementia, now have longer term care needs. These changes have obvious implications in terms of the demands placed on carers who themselves are getting older and in need of support.
- 2.5 A total of 9.2 million people across England and Wales are over the age of 65, an increase of more than 10 per cent in the past decade, with many more due to retire in the next few years. Overall another 2.1 million people are due to reach state retirement age in the next three years alone. The number of people aged over 90 rose by more than a quarter to 430,000 in the 10 years

We want to enable carers to make more choices for themselves and to have more control over their lives. We want services to recognise carers as individuals in their own right.

since the last census, a 26-fold increase in the past century (Source: Census 2011, ONS).

2.6 While the number of people needing care is set to rise, social trends could, in the future, have an effect on the number of available carers. The growth in the number of lone-parents, falls in birth rates, higher divorce rates, increase in the numbers of people living alone and greater family mobility may all have an impact on the numbers of people able to take on a caring role. In addition, the growing number of women who are employed outside the home will have implications as women have traditionally fulfilled the caring role.

Government policies for community care depend, in large part, upon the continuing contribution of carers; indeed carers are seen as forming the backbone of community care

2.7 A very large number of people who receive community care services to help them to manage their own lives are dependent on the care and support of a carer. Government policies for community care depend, in large part, upon the continuing contribution of carers; indeed carers are seen as forming the backbone of community care.

The national policy for carers

2.8 In 2008, the government set out its national carers strategy: 'Carers at the heart of 21st Century families and communities'. They laid out the following outcomes to be achieved by 2018:

- Involving carers in the decision-making process regarding the cared-for and supporting carers;
- Enable carers to maintain control over their life and not to be governed by caring;
- Reduce the impact of caring on their finances;
- Help maintain health and wellbeing of carers and ensure they are treated with dignity;
- Ensure young carers are not disadvantaged and ensure they are protected from inappropriate caring.

The coalition government in 2010 updated the carers strategy. In a report entitled: 'Recognised, valued and supported: Next steps for the Carers Strategy' they highlighted four key priority area for the next four years:

- **Priority Area 1:** Early identification and positive engagement with carers;
- **Priority Area 2:** Carers are not disadvantaged academically or at work;
- **Priority Area 3:** Services tailored to carers and cared-for persons to help maintain a family and community life;
- **Priority Area 4:** Focus on maintaining the physical and mental health of carers.

In October 2014, the government released an update and a further action plan in the four priority areas above for carers: 'Carers Strategy: Second National Action Plan 2014 – 2016'¹. In particular, progress was noted in relation to new legislative support for carers, policy reforms to support joined-up work between health and social care, and commitment from other sectors.

2.9 The 'Better Care Fund' (BCF) is a 'pooling' of the health and social care budgets. The fund will include £3.8 billion of which £1 billion will be based on integration of health and social care services, to improve:

- ✓ Emergency admissions;
- ✓ Delayed transfers of care;
- ✓ Effectiveness of reablement;
- ✓ Admissions to residential care;
- ✓ Patient and user experience.

In 2015/16 the national BCF funding was £5.3 billion (an additional £1.5 billion over expected funding). Nationally, social care is expected to spend 39 per cent of this budget.

2.10 NHS England's 'Commitment for Carers'² report was published in April 2014. To support this commitment to carers, health partners have produced resources for professionals including 10 Commissioning principles:

1. Think Carer, Think Family; Make every contact count;
2. Support what works for carers, share and learn from others;
3. Right care, right time, right place for carers;

¹ <https://www.gov.uk/government/publications/carers-strategy-actions-for-2014-to-2016>

² <https://www.england.nhs.uk/ourwork/pe/commitment-to-carers/>

4. Measure what matters to carers;
5. Support for carers depends on partnership working;
6. Leadership for carers at all levels;
7. Train staff to identify and support carers;
8. Prioritise carers health and wellbeing;
9. Invest in carers to sustain and save;
10. Support carers to access local resources.

2.11 The NHS 'Outcomes Framework 2010' highlights the need to support carers and incorporates carers as part of their measures:

- Focussing on carers wellbeing: 'Enhancing quality of life for carers; and health-related quality of life for carers'
- Listening to carer's views on services for the cared-for: 'Improving the experience of cared for people at the end of their lives'; and 'Bereaved carers' views on the quality of care in the last three months of life'.

2.12 The Royal College of General Practitioners³ (RCGP) has worked with the NHS to deliver the commitment to carers including development of 10 commissioning principles. They have also produced training resources and tools to help professionals better support carers, including the 'RCGP Caring for Carers Hub' - a resource for primary care health professionals to support and signpost carers. Furthermore to raise the profile of carers regional GP champions were appointed.

2.13 The 'Triangle of Care' was developed in 2010 in conjunction with Carers Trust⁴ and the Royal College of Nursing. The revised edition is produced by Carers UK⁵ in partnership with mental health services. It helps support carers looking after people with a mental health issue and promotes their wellbeing. The triangle of care in particular encouraged carer involvement and partnership working.

2.14 More recently with the implementation of the Care Act 2014, for the first time carers will be recognised in law in the same way as those they care for. It introduces key changes in support provision for carers such as carer's assessment for all adult carers on appearance of need rather than to only those providing regular and substantial care. Similarly, the Children's and

³ The **RCGP** is a network of more than 52,000 GPs and the voice of the profession on education, training, research and standards.

⁴ **Carers Trust** is the **UK's** largest charity supporting unpaid **carers**.

⁵ Carers UK is the only national membership charity for carers, **Carers UK** is both a support network and a movement for change.

Family Act 2014 states new rights to young carers and parent carers of children (those under the age of 18 years with disabilities).

- 2.15 The Children's and Family Act 2014 is primarily related to supporting young carers and parent carers of children (under the age of 18 years with disabilities). This act entitles young and parent carers to an assessment once the Council is aware of their caring role or if asked to by a carer. Carers are provided this assessment irrespective of the type and amount of care provided.
- 2.16 The Equality Act 2010 prohibits direct discrimination and harassment based on association and perception in respect of race, sex, gender reassignment, disability, sexual orientation, religion or belief and age, in relation to employment and other areas. This is embedded in all public sector policies and practice.

The local policy for Carers

- 2.17 Adult Social Care Outcomes Framework (ASCOF) is used both locally and nationally to set priorities for care and support, measure progress, and strengthen transparency and accountability. The ASCOF fosters greater transparency in the delivery of adult social care, supporting local people to hold their council to account for the quality of the services they provide. A key mechanism for doing this in Buckinghamshire is through councils' local accounts, where the ASCOF is already being used as a robust evidence base to support the councils' reporting of their progress and priorities to local people. There are seven ASCOF performance measures in place for carers (see section on Monitoring and Review 7.4).

The Carers Partnership Board brings together local service users and carers, local providers and County Council commissioners to advise and make recommendations on the joint development of health, social care and related services.

- 2.18 The Carers Partnership Board brings together local service users and carers, local providers and County Council commissioners to advise and make recommendations on the joint development of health, social care and related services.

2.19 Buckinghamshire's User⁶ Led Organisation (ULO) was established to develop strong user and carer involvement and dialogue across services provided by Buckinghamshire County Council (BCC), health, and adult social care. The ULO in Buckinghamshire is provided by Bucks Service User and Carer Organisation (SUCO), which was established in 2012.

Support for carers is an essential part of other key strategic developments within BCC and the CCGs strategies.

2.20 Support for carers is an essential part of other key strategic developments within BCC and the CCGs such as mental health, older people, primary care and assisted technology and dementia strategies. Key commissioning partners and providers can optimise the use of resources and harness the effort better by stronger strategic planning and more joined-up approaches to carer support.

2.21 Carers Bucks is BCC's formal commissioned carers' advice, information and guidance service. As a partner in the development of this strategy the organisation will be important to support local implementation. BCC and the CCGs cannot determine the priorities of the voluntary and provider sectors. However, they can encourage them to consider and take forward the actions within this strategy to support carers. In particular, carer organisations, such as Carers Bucks, Age UK and Alzheimer's Society have a key role in implementing the strategy, and some of the actions will be specifically directed to them.

2.22 BCC and the CCGs receive a wide range of good practice examples/case studies from the statutory, voluntary and provider sectors. These good practice examples demonstrate the commitment of partners, voluntary sector and the private sector to ensuring support for carers in a meaningful and sustainable way.

2.23 Prevention Matters Buckinghamshire has a strong emphasis on early intervention. A focus on anticipatory⁷ support for carers is essential as part of their work. However, a greater emphasis on early identification and

⁶ The term "user" refers to people who use support services in a local authority area. This includes people with disabilities, such as those with physical impairments, sensory impairments, learning difficulties or mental health issues. It also includes informal carers.

⁷ Process designed to support patients living with a chronic long-term condition to help plan for an expected change at some time in the future

preventative support in relation to both the carer and cared-for person, which does not have to be complex or expensive, is essential as it can prevent or delay the need for crisis intervention and is therefore more cost-effective.

- 2.24 Buckinghamshire Public Health sees merit in carers in the relevant age bracket having access to and being enabled to take advantage of health checks where effects of obesity, lack of exercise, and alcohol and smoking can be detected at an early stage, which can be associated with diabetes and cardiovascular disease, as well as lung and liver disease and cancer. There are raised dangers of these factors, because of the stresses in a carers caring role. However, Public Health continues to look at creative and flexible solutions to facilitate such health checks and services when carers cannot easily attend appointments.
- 2.25 Buckinghamshire's 'Health Inequalities Project' funded by health and social care is looking at high-risk primary prevention targeted on health inequalities. This project intends to tackle health inequalities through identifying the key health inequalities issues encountered by carers.
- 2.26 'Self-Directed Support' seeks, amongst other things, to give the council power to provide direct payments to carers. Self-directed support is one form of personalised support which enables carers to choose how and by whom their support is provided. Evidence suggests that self-directed support and direct payments can lead to improved outcomes for individuals, families and communities. The use of direct payments can help meet the needs of some sections of the carer population, including BME service users and carers.
- 2.27 The ADASS⁸ 'Carers and Safeguarding Adults' paper, April 2011 identifies carers in safeguarding roles as partners, informants, vulnerable to abuse themselves or as abusers. Their aim is to improve practice to achieve desired outcomes for:
- Carers speaking out about abuse and neglect;
 - Carers experiencing abuse or neglect from their cared-for person, professionals, organisations or the community;
 - Carers who intentionally or unintentionally cause harm themselves.

⁸ Association of Directors of Adult Social Services (ADASS)

Professionals in health and social care have a duty to respond to safeguarding concerns raised by a carer.

ADASS state that key factors common in carers both at risk from harm or causing harm themselves include:

- Deterioration in carers own health and wellbeing as a result of their caring responsibilities.
- Carer isolated with no practical or emotional support.
- Cared-for person's healthcare needs exceed the carers ability to meet them.
- The carer is angry, abusive or aggressive.
- It should be noted that carers of people with dementia are at high risk of suffering depression and symptoms of this should not be overlooked.
- Financial abuse from the cared-for towards the carer, particularly where substance abuse is involved.
- Carer and or cared for person is being stigmatised or abused by members of their local community.
- For various reasons carers do not always report abuse they are being subjected to by the cared-for person.

ADASS identify two categories of carers themselves causing harm:

Unintentional Harm:

- Abuse and neglect are not necessarily intentional and can be caused by a lack of or information or by stress or isolation. For example inappropriate moving and handling or restraint practices;
- The effects of ageing can take its toll on a carer and lead to mutual caring. In some cases there can be a role reversal where a previously dominant family member loses their dominance. This can lead to anxiety and conflict;
- The professionals aim should be to take proportional action, which reflects the desired outcomes of the parties involved.

Intentional Harm:

- Where there is intentional harm inflicted by a carer it is important to ensure a consistent focus on the needs of the person at risk from harm.

There should be a careful assessment and a risk enablement approach. The outcomes sought should be person centred not process driven with proportional action to reflect desired outcomes. Exclusion of agencies from the situation can increase the danger of harm;

- Cases of deliberate harm should always engage safeguarding or police input as appropriate.

Buckinghamshire Safeguarding Vulnerable Adults Board⁹ recognises safeguarding is complex and in particular for carers. Sometimes there are no perfect answers and adult carers and young adult carers needs and circumstances can also be very diverse. The Board continues to explore issues around improving practice and securing desired outcomes for:

- Carers speaking up about abuse or neglect within the community or within different care settings;
- Carers who may experience intentional or unintentional harm from the person they are trying to support, or from professionals or organisations they are in contact with;
- Carers who may unintentionally or intentionally harm or neglect the person they support.

2.28 Buckinghamshire Healthwatch is commissioned by BCC and the CCGs to identify common problems with health and social care based on people's experiences. Healthwatch will:

- Recommend changes to health and social care services that they know will benefit people.
- Hold those services and decision makers to account and demand action.

2.29 Quality in Care ensure that care home providers are providing good quality services to people living in their homes. They work closely with both carers and paid care workers to ensure that the people they care for experience good quality care.

⁹ The Buckinghamshire Safeguarding Adults Board (BSAB) is a group of statutory, private, voluntary, and independent organisations across Buckinghamshire who work together to empower and protect some of the most vulnerable members of our community

2.30 BCC has commissioned POWhER Community Advocacy Services for people who need support to deal with an issue they are facing. Services are open to adults aged 18 or over, and people can generally use community advocacy services if they are:

- In a situation where they feel vulnerable, discriminated against or at risk of abuse (financial, emotional, physical, sexual, psychological or institutional),
- Finding it difficult to put their views across or don't feel they are being listened to;
- Feeling that they do not have support from someone who has their best interests at heart;
- Facing a major life change that could mean that they will need to access support services.

Advocates help people understand their rights and the options open to them, help them speak up and have their voice heard. Advocates can help with writing letters, making phone calls, arranging and attending meetings. The advocates only act on instructions from their clients.

2.31 Economic Case for investing in carers: The Care Act (2014) clearly stipulates local authorities are not required to charge carers for support. In Buckinghamshire we are giving careful consideration to charging carers, as they may be reluctant and refuse services that come with charges for their own support, mostly on the basis of affordability. If services are refused, then this reduced support is highly likely to lead to increased 'carer breakdown' where carers are unable or unwilling to continue caring, resulting in a potentially significant increase in costs to the health and social care sector. The Care Act guidance (section 8.50) however, does state there may be circumstances where a nominal charge may be appropriate.

Analysis carried out by London Borough of Newham and Surrey County Council has found that the potential increase in local authority responsibilities could vastly outweigh the investment in carer services and shows that any potential charge to a carer is unlikely to represent value for money.

Proposed national policy developments for carers

2.32 The new national strategy due to be developed early 2016 will look at best international practice and examine what more can be done to support both existing and new carers. The Government's vision is that by 2018, carers will be universally recognised and valued as being fundamental to strong families

and stable communities. Support will be tailored to meet individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, whilst enabling the person they support to be a full and equal citizen.

- 2.33 The review of Deprivation of Liberty Safeguards¹⁰ (DoLS) has been accelerated. The original review, due in 2017, is now to be reported back by the end of 2016. This was because in 2014 the Government has said that DoLS was not fit for purpose.
- 2.34 A recent report published by Alzheimer's Society¹¹ on dementia care in Britain, following a survey of 1000 GPs, found that dementia patients are increasingly relying on friends and family. The report will make key recommendations to the NHS to support patients and carers.

¹⁰ The Deprivation of Liberty Safeguards (DoLS) are part of the Mental Capacity Act 2005. They aim to make sure that people in care homes, hospitals and supported living are looked after in a way that does not inappropriately restrict their freedom.

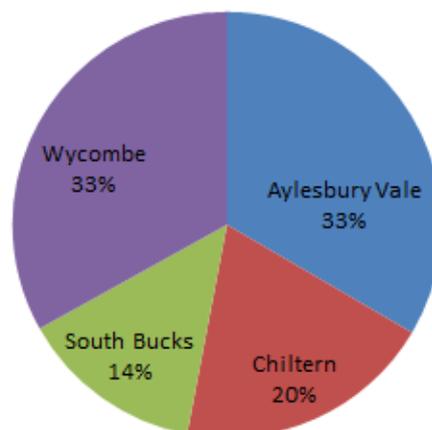
¹¹ Published on 6th July 2015, as part of on-going project 'Dementia 2015: Aiming higher to transform lives'

Needs and demand analysis

What we know about carers in Buckinghamshire

- 3.1 Carers play a crucial role in the delivery of health and social care provision nationally. In England 10.9 per cent of the population were unpaid carers in 2011. Economic value provided by Buckinghamshire carers in 2011 was £716 million.
- 3.2 Nationally, the prevalence of caring is the highest amongst those aged 50-64 (20 per cent). There are 16 per cent more female carers (3.1 million) than male carers (2.3 million). By ethnicity a higher proportion (around 11 per cent) within the white ethnic community (British, Irish or travellers) are likely to be carers, in contrast to Asian, African or Chinese communities where a lower proportion take on a caring role (around five per cent).
- 3.3 Furthermore, nationally there has been an increase in proportion of unpaid carers in the 2011 census compared to 2001. This translated into 581,441 more people assuming a role of carer in 2011 in contrast to a decade ago.
- 3.4 In 2011, 49,514 people (9.8 per cent of the population) in Buckinghamshire provided unpaid care. This is close to the national average. Two thirds of carers in Buckinghamshire are resident in Aylesbury Vale or Wycombe Districts.

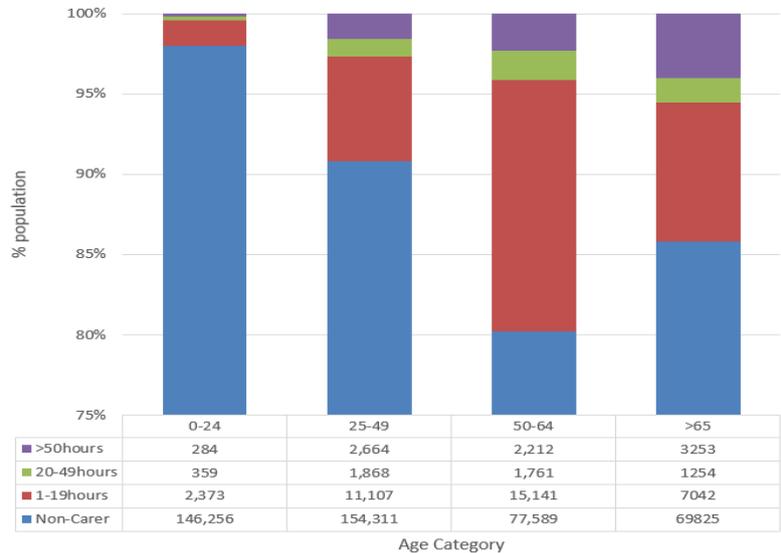
Distribution of carers by districts (Source: Census 2011)



- 3.5 As with the national prevalence the age band with the highest proportion of carers in Buckinghamshire is in the 50-64 range where nearly 20 per cent of

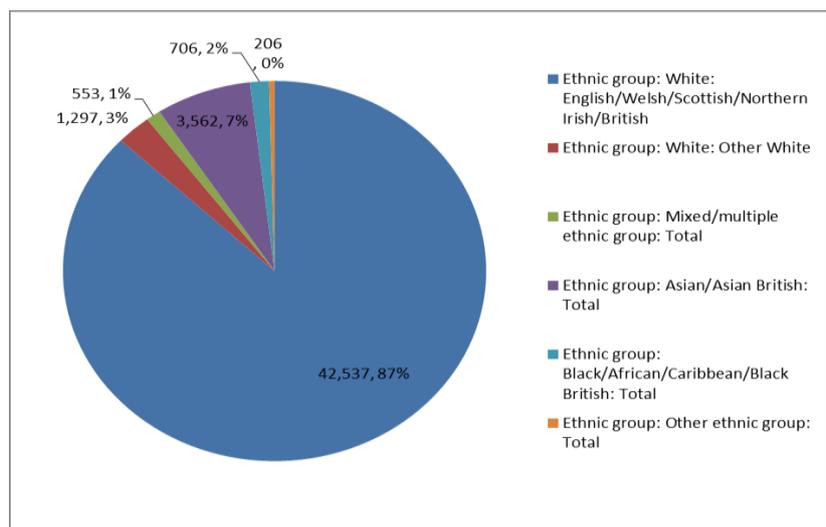
the population provide informal care and 58 per cent of informal carers in Buckinghamshire are female.

Proportion of all carers by age category in Buckinghamshire (Source Census 2011)



3.6 In 2011 (census) of all the self-identified carers – 13 per cent (6,324) were from a BME¹² background. The largest ethnic minority group of carers is of Asian ethnicity group which forms seven per cent of the carer population in Buckinghamshire.

Ethnic distribution of unpaid carers in Buckinghamshire (Source Census 2011, ONS)



¹² Black and Minority Ethnic background

3.7 Overall, in Buckinghamshire the numbers of carers has increased by 13 per cent from 43,821 in 2001 to 49,514 in 2011. By 2012 there were 5,981 known carers in Buckinghamshire from:

- Buckinghamshire County Council
- Carers Bucks
- SUCO
- Young Carers
- Age UK

3.8 Carers Bucks survey, conducted by them in February 2015, included 5,920 carers registered with them. On average Carers Bucks receive 102 new referrals per month. This is expected to rise following the implementation of the Care Act.

3.9 The majority of known carers provided more than 50 hours care per week. However, it appears in the general population of carers they are a minority. The majority of carers appear to provide 1-19 hours care per week. Previously emphasis was placed on carers who provided substantial care. Therefore those providing less than 50 hours care were less likely to self-identify or be referred to services and are more likely to be 'hidden'. Of the 49,514 self-identified, potentially nine in 10 carers are likely to be hidden.

There has been a large increase (38 per cent) in the number of people providing 20+ hours of care per week from 10,000 people in 2001 to 14,000 people in 2011

3.10 There has been a large increase (38 per cent) in the number of people providing 20+ hours of care per week from 10,000 people in 2001 to 14,000 people in 2011.

3.11 In Buckinghamshire's two clinical commissioning groups the proportion of self-identified carers in the population on average was 18 per cent in July 2014 Buckinghamshire has a similar proportion of carers compared to the national average.

3.12 More than half of carers (57.8 per cent) in Buckinghamshire care for someone with a physical disability; the next two most common conditions are long-standing illness (39.5 per cent) and problems connected to ageing (36.7 per cent).

- 3.13 Three quarters of carers reside with their cared-for person and the majority of carers (67.2 per cent) have been caring for more than five years. Carers may help cared-for persons in many ways - physically, practically, socially, emotionally and maintaining health. (Source: Census 2001 & 2011, ONS).
- 3.14 While there may be common themes in relation to the basic need for support, we know that people who provide care for others are a very diverse group, with equally diverse needs. For example, an older person caring for their partner with dementia will have very different needs to a parent caring for a severely disabled child or a person caring for someone who has suffered a head injury in a road accident, or a young adult carer looking after a single parent with mental health problems.

Young carers in Buckinghamshire

- 3.15 In 2011 there were 1,875 self-identified young carers. This is 1.5 per cent of the total population of young people aged 0-19. This represents a 36 per cent increase over 10 years.

The age band with the most substantial increase in young carers is in the 0-9 year age group where there has been a 126 per cent increase over 10 years. In 2011 carers aged 0-9 formed 11.7 per cent of young carers. Majority of young carers either reside in Aylesbury Vale (36 per cent) or Wycombe (37 per cent), (Source Census 2011, ONS).

District	Young Carers	Total Young Persons	% Young Carers
Aylesbury Vale	685	43101	2%
Chiltern	300	23226	1%
South Bucks	202	15547	1%
Wycombe	688	42348	2%

- 3.16 The majority of young carers (81 per cent of young carers) provide less than nine hours of care per week. However, a significant number (8.4 per cent) do provide more than 50 hours of care per week.
- 3.17 The age group 16-19 contains the highest number of young carers (875). This translates into 47 per cent of all young carers being aged between 16-19 years. Overall there are more female than male young carers. 54 per cent of all young carers are female.

3.18 There is particular concern for the 18 -24 year old group, based on the quarterly release of NEET (not in education, employment or training) and NET (not in education or training) figures¹³, in terms of including a disproportionate number of young carers, whose lives might be blighted by missing the educational and career progression boat in early adulthood.

¹³ <https://www.gov.uk/government/collections/statistics-neet>

Supply analysis

Resources for carers in Buckinghamshire

4.1 Resources for services to people with care needs and for support to carers are within local authority's social care and the pooled budget (BCF). Other local authority budgets will also be relevant to carers, especially in relation to welfare benefits, housing and Children's Services.

4.2 Buckinghamshire's Care Act stocktake for October/November 2015 showed:

Care Act 2015 Stocktake		
	In 2014/15	From 1 April 2015 to 30 September 2015
Total number of adult social care assessments (this includes reviews)	3826	2799
Total number of assessments where the eligibility threshold was met	2599	1594
Total number of carers who were given information and advice and/or signposted to other universal services	336	77
Total number of carers who were assessed for care and support	752	351
Total number of carers who were assessed for care and support who met the eligibility threshold	404	134
Total number of carers who received council funded services	261	149
Total amount your council spent on social care assessments (this includes reviews) (£)	£1,780,9000	£820,2000
Total amount the council spent on respite care	£893,000	£444,000
Total amount the council spent on direct payments to carers	£684,000	£247,000
Total amount the council spent on services for carers (excluding assessment costs)	£159,4000	£969,367

4.3 We recognise that within existing financial resources, reducing avoidable hospital admissions by providing appropriate support and services in the community is the single most significant area that can deliver better outcomes for people. It also has the potential to release resources to use elsewhere in the health and social care system.

4.4 In 2012/2013 in Buckinghamshire 2,405 carers received some form of service (including information only). Of these, 51 per cent were aged between 18-64, while the remainder were older carers over 65.

The majority of these carers received carer specific services (90.6 per cent). Again 51 per cent of those who received carer specific services were aged between 18- 65, while the remainder were older carers over 65.

4.5 The local authority faces a worsening funding situation with limited resources, increasing cost pressures and underlying funding shortages, demographic pressures combined with high expectations of the services we arrange and provide.

As a result, going forward there needs to be even greater efforts to use the limited funding available to support carers to best effect . We recognise value and support the work of carers and their dedication and therefore the strategy aims to make the most effective use of funding available to help support carers. There are a number of examples of this in the action plan set out to deliver this strategy, for example key actions such as:

We recognise value and support the work of carers and their dedication and therefore the strategy aims to make the most effective use of funding available to help support carers.

- Early identification, intervention and support to prevent unnecessary crisis.
- Improving accessibility of services for carers .
- Getting best use of the experience and knowledge of carers in care planning for service users, where appropriate ,involving them in the effective commissioning of services, improve information to carers both generally and specifically (e.g. support given when the person they care for is discharged from hospital).

What we are already doing in Buckinghamshire for carers

Statutory services for carers	
1.	Prior to the Care Act duties we have been offering 'carers assessments'. This was initially given to carers who were deemed eligible for a social care service as a carer grant.
2.	With the introduction of the Care Act we now offer carers direct payments to give more flexibility, choice and control over the services they receive.
Identifying and involving carers through support services	
3.	BCC, Carers Bucks and SUCO now have an established database identifying carers.
4.	Carers Bucks, in partnership with the CCGs, have opened a Carers Hub at Stoke Mandeville hospital in Aylesbury enabling carers to receive information, advice and support in the hospital.
5.	Carers Bucks are working with Chiltern CCG and GP practices on pilots in the south of the county to identify and support carers within their GP practices, with specialist staff available to support carers.
6.	Buckinghamshire's Drug Alcohol Action Team (DAAT) recently commissioned Carers Bucks to promote identification of, and support to, carers of people with substance misuse problems.
7.	The public sector is required to ensure that equality duties on race, disability and gender are integrated into all the functions and policies of social care and health. BCC and the CCGs need to assess the impact of policies to ensure that we do not inadvertently create a negative impact for equality groups.
8.	The Carers Partnership Board has a role in evaluating the change to services for carers and cared-for person. Carers are engaged in the decisions made on social care and health services that affect them.
9.	The Executive Partnership Board (EPB) provides an opportunity for partners and voluntary sector providers to work together to improve the lives of local communities. The EPB actively involve service users and carers.
10.	Carers Bucks support and promote the wellbeing of carers, and ensure that carers are represented and engaged in service developments and policy changes through support groups across the county and through service specific workshops.
11.	SUCO, Healthwatch and Quality in Care are established to develop strong user and carer involvement with dialogue across all services provided by BCC, Health and Adult Social Care. Service users and carers are involved in shaping and influencing future social care, health and other services they receive.
12.	There is carer involvement and participation in procurement of new services, ensuring that services properly take account of carers' needs.
Providing Information and Advice for carers	
13.	National and local carer and disease specific organisations, such as Carers UK, Carers Trust, Carers Bucks, Alzheimer's Society, Stroke Association,

	Parkinson's Disease Society, Age UK, provide a wide range of information and advice to carers through their publications, websites and support groups
14.	Through Prevention Matters local carers' centres have a crucial role in providing a wide range of comprehensive information and advice, including carer information packs tailored to different caring situations, benefits and health and well-being advice.
15.	
16.	The new BCC digital service will provide comprehensive up-to-date information on all aspects of community care for carers and young adult carers and will cover issues such as - how to get a care needs assessment, care options, including domiciliary care and residential care and how much that care costs.
Providing a range of support for carers	
17.	Carers Bucks also support carers through a range of services including a streamlined pathway for carers to access services and support. <ul style="list-style-type: none"> • A range of tailored training and guidance on specific topics. e.g. emotional, and financial issues.
18.	A carer pathway approach is currently being developed helping to ensure carers receive the appropriate support based on their needs. Depending on their role, social care and health professionals may come into contact with carers face to face, or be involved in planning services for them or the people they look after.
19.	Care managers are introducing person-centred approach to assessments and support plans, so that there is choice of support that is flexible and tailored to individual needs.
20.	Carers' Flexible Breaks provided through referrals from the GP are funded by the NHS. The health payment is for carers over eighteen years of age who look after or provide regular and substantial help to family members, neighbours or friends who are sick or disabled, vulnerable or frail. The fund is aimed at carers, whose health and wellbeing may be affected, to access a range of flexible breaks to improve this and to sustain them in their caring role. So far 1,935 (Dec 2015) carers have been supported by the 'Flexible Breaks' service.
21.	There are also examples of volunteers supporting carers they had not previously known. This type of volunteering is usually facilitated by organisations such as Carers Bucks, Age UK and the Alzheimer's Society. The Alzheimer's Society will launch its dementia training toolkit later this year to enable volunteers to tailor their befriending support to the needs of those with dementia and their carers.
22.	Direct payments and personal budgets are available to carers following an assessment of their needs.
23.	POWhER provide advocacy services for those who are vulnerable.
24.	Emergency respite care is available where, for example, a carer has to deal with an emergency and needs respite at short notice. There are various means to provide such support, such as a sitter service as a one-off or on an ongoing

	basis.
25.	BCC also has a Rapid Response Team, which has a home care team to provide emergency respite.
26.	Care management teams and Carers Bucks provide holistic and responsive services, which address all aspects of life circumstances, such as income maximisation, debt advice, access to affordable credit and supporting financial capability.
27.	Carers Bucks provide carer and peer support groups within a safe, listening environment. The demand for these services has increased over the last year.
28.	The new Public Health initiatives Lifestyle Gateway and the CCGs Stay Well-Live Well are preventative models with potential to help improve the mental health and wellbeing of the general population, including carers. This Public Health initiative launched summer 2015 covers four services: weight management, smoking cessation, alcohol; and get healthy coaches - initially in Aylesbury and Wycombe.
29.	BCC and Public Health are going out to carers support centres to provide more carer awareness and support and to offer carers the chance to have a health check at the centres.
30.	The Buckinghamshire Safeguarding Adults Board continues to work in partnership on exploring issues around improving carers health and wellbeing by encouraging carers to speak up about abuse or neglect within the community, or within their own care settings.
Providing employment and employment training opportunities for carers	
31.	The Job Centre Plus programme gives providers the flexibility to tailor services based to individual needs.
32.	Many employers have developed carer-friendly policies and effective workplace practices, enabling carers to remain in, or to return to, work.
33.	Carers Bucks have greatly improved outcomes for carers achieved through their carer training programmes, including: being more positive about caring; being more confident in the caring role; and having a more positive impact on the carer's health. A lot of valuable and outcome-focused carer training is being undertaken.
Supporting young adult carers	
34.	Developing a young adult carers assessment tool is underway which focuses on preparing for adulthood.
35.	The transitions team are developing a business process for young carers so they can transfer into adult services if they are eligible.
36.	BCC is working with Carers Bucks to look at what alternatives we can offer if young people are not eligible.
37.	Universal support that assists school leavers to make informed and positive choices is, of course, also available to young carers. 16+ Learning Choices provides such an opportunity.

What we still need to do for carers in Buckinghamshire

- 5.1 Increased carers assessment will result in more carers qualifying for services, particularly as changes in the carers' assessment will result in greater emphasis on supporting carers own needs in addition to their caring responsibilities.
- 5.2 Further standardisation of carer support may increase the services that could be provided. Capacity for both carer specific services and information-only services will need to be stepped up. In particular, as more hidden carers who provide less intensive care may be assessed more 'information-only' services may need to be provided.
- 5.3 There appears to be a small under-representation of ethnic minority groups in the local databases of known carers. For example, seven per cent of carers were Asian in the 2011 census estimates, but the local survey of known carers reported a lower proportion of Asian carers (5.8 per cent). This is supported by literature which states that due to cultural barriers ethnic minority carers are less likely to access services and remain hidden.
- 5.4 Ethnic carers from the southern part of Buckinghamshire are more actively interacting with services and are thus better known to services. The northern part of the county is more rural and therefore might have poorer access to services.
- 5.5 An increase in demand for services is expected from the implementation and awareness brought about by the Care Act, above and beyond the expected increase seen over the last few years.

Many carers say that it is a privilege to care for a loved-one and that caring can bring rewards and a great deal of satisfaction

Carers in their caring role

- 5.6 Many carers say that it is a privilege to care for a loved-one and that caring can bring rewards and a great deal of satisfaction. However, being a carer means that a loved-one, friend or neighbour is ill or frail or has a disability or a

substance misuse problem, which can have a significant impact on carers' lives. Sometimes carers look after family members and others in very difficult and challenging circumstances, and because they feel obliged rather than because it is what they want to do. Statutory agencies, voluntary and other organisations providing services to the cared-for person should never assume that people want or choose to be carers or make assumptions about the time commitment people are prepared to give in their caring role.

As far as possible carers, whatever their circumstances should enjoy the same opportunities in life as other people without caring responsibilities and should be able to achieve their full potential as citizens.

- 5.7 As far as possible carers, whatever their circumstances should enjoy the same opportunities in life as other people without caring responsibilities and should be able to achieve their full potential as citizens.
- 5.8 Carers are important advocates for those they care for, providing important practical and emotional support. It is vital for health and social care commissioners to invest in carers, as that will have a positive impact on health and social outcomes for both the cared-for and carer. A recent Carers UK survey revealed that 4 in 5 carers report that better care means 'dignity, respect and a better life for the person they care for'.
- 5.9 The Adult Social Care Biennial Carers Survey carried out by BCC in 2014 (see Appendix One) found that of 339 carers:
- 44 per cent reported having no health issues;
 - 66 per cent did not receive enough encouragement in their role, 16 per cent did not receive any at all;
 - 75 per cent were not able to spend as much time as they would like doing things they valued and enjoyed, and 10 per cent said they were unable to do anything they valued or enjoyed;
 - 66 per cent did not have enough control over their daily lives, and 12 per cent had no control. (This was most likely in the 45-85 age groups though this was also the largest group of respondents. Carers reporting that they

did not have control over their daily lives were less likely to report being able to look after themselves);

- 16 per cent of carers reported that they were neglecting themselves in terms of sleeping and eating well. None of these respondents indicated that they had control over their daily lives;
- 13 per cent felt socially isolated and 48 per cent reported not having enough social contact.

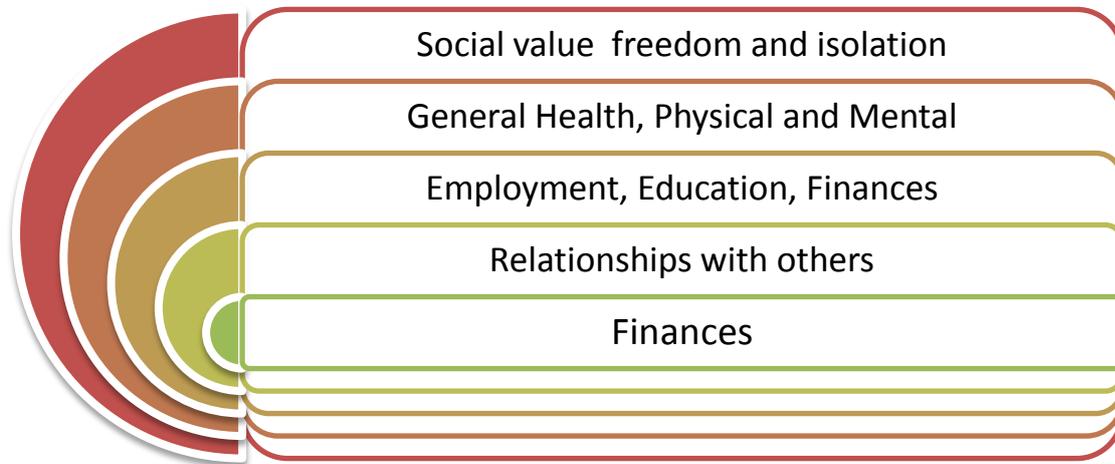
The survey also asked carers about recognition and motivation to improve wellbeing, and the impact of poor wellbeing on their carer role; the findings were:

- Carers who found themselves at crisis point were found to have significantly higher levels of depression and anxiety than carers who were coping. Carers with higher depression levels were less likely to be able to leave the house;
- One in four carers had needed medical treatment as a result of a breakdown in their caring role. Carers responding to the survey reported serious health problems such as heart attacks and hernias.

5.10 Of the wider factors influencing the wellbeing of the carer, findings were:

- The condition of the person they are caring for (for example if they have a poor relationship with the person, if the person's condition is deteriorating or has significantly altered their personality, e.g. if they have a brain injury).
- A breakdown in the caring role can force carers to make sudden decisions, such as quitting work or university, or purchasing expensive care. This can lead to further strain.
- BME carers found difficulties in accessing health and social care and stated issues such as stigma, language, stereotypes and assumptions as barriers.
- The age of the carer – 25 per cent of carers aged 35-44 reported feeling socially isolated as did 21 per cent of carers aged between 45 and 54. Carers aged 85+ were the least likely to feel socially isolated.

5.11 The 'Adult Social Care and Public Health Needs Analysis 2015' (see Appendix Two) looked at the impact of caring for both the cared for and the carer across a number of health and social outcomes:



5.12 The key recommendations that emerged from both the carers survey and the needs analysis were:

- Increase in demand for carers services;
- Acknowledging that services need to be tailored to the diverse carers community;
- Improving services for the people they care for will improve carers health and wellbeing;
- Improving the quality of information, advice and guidance provided to carers in relation to services on offer, finances and employment rights;
- Increasing the social value of carers and recognising carers in society;
- Developing a carers passport enabling better accessibility to services for carers, such as parking permits;
- Improving employers' awareness and develop emergency pathways for employment and education progress;
- Streamline services with better collaborative approach between health and social care;
- Early identification of hidden carers;

- Raising carer awareness on hidden risk of ill health and providing services that are flexible and timely;
- Increasing access to public health services and health checks for carers;
- Building in preventative approaches to services;
- Building up resilience in young adult carers.

Key priorities

The future vision for carers in Buckinghamshire

- 6.1 The gap analysis and the recommendations from what carers told us form the basis of our vision for the future for carers. Our vision will be to improve the quality of life for carers in Buckinghamshire by supporting, recognising and valuing carers. To put our vision into practice the strategy considers how well our current services are doing to support carers and identifies what more we still need to do to achieve our goal.

Improve the quality of lives for carers **Our commitment to carers in Buckinghamshire**

Support , value and recognise carers as equal partners in care

**Support and give carers confidence to have a life of their own
outside of caring**

Involve carers in planning and shaping services

Recognise that Carers need flexible and responsive support

- 6.2 In drawing up the strategic vision for the next three years the Council consulted with reference groups of carers and organisations representing carers across the county to find out what they saw as solutions to the difficulties they face in carrying out their caring role. Carers identified four key principles underpinned by the key outcomes they would like to achieve as carer:

To be recognised as equal partners

- Carers must be recognised and included as real and equal partners at every level of public sector planning and service delivery – from individual care planning to designing a service;
- A carer has a unique relationship with the person they care for. In their partnership with carers, other agencies or care providers should recognise and value that relationship, and the care given by the carer in their joint responsibility for the person being cared for;
- Carers must be given at least equal status with other providers of care to their cared for person.

To have a life of their own outside of caring

- Carers need rest, relaxation and a social life and if they wish to work outside the home, they should have the opportunity to do so;
- Carers are supported and empowered to manage their caring responsibilities with confidence and be in good health, as well as have a life of their own outside of caring;
- Have the ability to combine caring responsibilities with work, social, leisure and learning opportunities (to retain a life outside of caring);

To be involved with planning services

- Improve partnership working with other sectors and organisations;
- Carers are fully engaged as participants in the planning and development of their own personalised, high-quality, flexible support and are not directed into unsuitable support;
- The same principle applies to carers' involvement in the services provided to the people they care for.

To receive flexible support

- Professionals should recognise that carers are individuals with their own needs, caring for people with a huge range of needs and abilities in what can be very complex and emotionally charged relationships, so services should be personalised and where possible self-directed;
- One solution will not fit all – carers need real choices based on relevant, timely and accessible information.

6.3 These key principles and outcomes are fortified by the 'National Carers Strategy Second National Action Plan 2014 – 2016'¹⁴ and the NHS 'Commissioning for Carers Principles 2014'¹⁵. In its broadest sense this means an inclusive society in which carers are reaffirmed as partners and are active participants in decisions about the cared-for and other support services.

¹⁴ HM Government Recognised, valued and supported, Next Steps for the Carers Strategy 2010

¹⁵ The Commissioning for Carers Principles form part of NHS England's Commitments to Carers, published on 7 May 2014, and the RCGP Supporting Carers in General Practice Programme

The knowledge and skills of carers need to be harnessed to make decisions about the shape and structure of services.

- 6.4 To ensure that all the recommendations at both national and local level were properly addressed and aligned to the key principles and outcomes further carer engagement workshops were carried out in July 2015.
- 6.5 The previous carers strategy has seen significant progress in implementing aspects of these principles. However, we fully recognise further work is still required. The following key priority areas emerged from the carer workshops for key activities to be formulated into an action plan so that we can improve carers services over the next three years.



**Identification
Equality and
Interface with
Carers**

NHS and Social care professionals are best placed to identify carers through their contact with patients and their families.

Integrating carer identification into the core professional role of health and social care supports carer identification and signposting to support

Carers want to be treated as equals and be treated in the same way as others who have challenging lives and situations at points in their lives. For instance parents with young children often have much more flexibility in their working hours.

Carers should be involved in planning and shaping the delivery of services and support to ensure the best quality services and support, delivered in a personalised way. This is an opportunity to voice their experiences and views, for instance in the early stages of procuring a new service to the later stages of contract monitoring the service.

**Information,
Advice and
Guidance for
Carers**

Carers who are new to caring often say that the priority for them is to have information and advice about the condition or illness of the person they are caring for. They may require a different type of information as the illness or condition changes. They would like the right type of information at the right time, depending on their particular circumstances. They also want up-to-date information, sometimes they are provided with information on services that is out-of-date.

Specialist health professionals can play an important role in providing condition-specific information that can help carers to understand and deal with difficult or challenging symptoms. Carers often need assistance to navigate in and around both statutory and non-statutory services and organisations

Many carers say that to receive information from GPs and other healthcare staff on the condition of the person they care for would help them in their caring role. They believe that they would be better equipped to care for their relative.

There is evidence to suggest that when carers are provided with appropriate information and engaged in the care planning, the outcomes for the patient and carer are enhanced. The overriding principle is the need to consider the best interests of the patient and carer.

Flexible Range of Support for Carers

Carers want services to be flexible where there are a range of services available that they can go to and choose from. People can continue to be carers, in a different way, for example, when the person they are caring for moves on to independent living or into a care home. Caring at end-of-life is particularly difficult and the carer may need support after their relative dies. Equally carers who are new to caring often say that the priority for them is to have information and advice about the condition or illness.

Carers frequently report the difficulties they encounter and the barriers they face in their day-to-day caring role. Some say they have benefited from support which has then been withdrawn or that there is a disjointed approach to the delivery of support from different professionals. Carers themselves often have to use their limited and precious time and energy to facilitate the connections to be made amongst the various professionals.

Carers often experience disjointed approaches and a lack of joint working, for example at times of transition when their child with a learning disability leaves school. The transition from children's to adult social care services can be particularly traumatic and therefore there needs to be involvement from carers and key professionals at appropriate times during the transition.

Carers Health and Wellbeing

Carers want recognition of the emotional impact and the physical demands of caring, both of which can adversely affect a carers' health. It is important to prevent deterioration in health as a result of caring and to promote good health, recognising that carers - like anyone else - can experience poor health unconnected with caring. Carers' health can be protected if the range of support is delivered according to individual needs. A sensitive and supportive carer's assessment/carer support plan can reduce stress and anxiety. The emotional impact of caring for a relative or friend can be immense.

Caring, for example, for a partner or relative with dementia or other neurological conditions, or with a severe disability or long-term or fluctuating condition, or for a child with special needs, can often affect a carer's emotional wellbeing more than their physical health. Carers can become socially isolated and ground down by trying to get services in place for the person they care for.

The major health concerns are related to stress, anxiety, emotional health and wellbeing generally, and the physical strains of caring - especially back problems through lifting and handling. Many carers are concerned that they cannot afford to be ill, and some feel unable to continue with their caring role. Carers who do say they are able to cope often worry about increasing age and their own personal health problems.

Employment and Training for Carers

Many carers want support to remain in employment as work provides an income and it is what people generally do, or want to do. Others want to access work, training or further education. Other carers who cannot work due to age and/or level of caring responsibility would like support to have a good standard of living and not experience financial challenges due directly to the consequence of caring.

Carer employment, skills development and lifelong learning, recognising the important role of carer-friendly and flexible working are an important consideration for carers. Taking on a caring role should not mean that people have to give up work to care. If people have to leave paid employment, reduce hours of work or move into a lower skilled job, they can experience financial hardship through loss of earnings

In recognition of the key role they play in providing care, carers should get similar opportunities for training as the paid workforce. Carers who receive training feel better supported in their caring role and more confident. Training should address the broad spectrum of the emotional impact and practical demands of caring. It should include moving and handling, managing medication, managing carers' own health and well-being, personal development and safeguarding issues.

Furthermore, a well-informed, knowledgeable, trained and skilled health and social care workforce is essential to help improve the lives of carers and young adult carers. Health and social care staff should have a proper appreciation of the role of carers and *young adult carers* and commit to engage with carers as equal and expert partners in the design and delivery of health and social care services.

Young Adult Carers

Transition is a key part of everyone's life. The demands of coping with change and moving on from that change can have a significant impact on young carers, who have to cope with the same transitions as their peers whilst balancing the stresses of caring for a parent, sibling or other person in their lives. Many young adult carers encounter these difficulties at a time when the dedicated young carers' service that supports them is no longer able to do so, either because of capacity issues or only funded to the age of 18. There is a danger that their progress into further education or employment might be blighted

There are very few examples of 18-25 year old carers seeking support from the services that support adult carers, as they don't tend to identify themselves with these services, which have tended to support older carers. Young adult carers want to have more choices and opportunities. There should be a focus on early identification of those at risk of disengagement and effective early intervention to sustain their engagement through learning, training and employment.

Taking the strategy forward

- 7.1 Buckinghamshire County Council and the Clinical Commissioning Groups role in respect to supporting carers will be to deliver the vision set out above and implement the action plan over the next three years.
- 7.2 This strategic context provides the reference point, on a Buckinghamshire wide basis, for Partnerships and Health and Wellbeing Boards, other statutory agencies and the voluntary and provider sector to locate their plans of action. BCC will be the lead in this area and will help to support local implementation, and determine local priorities.
- 7.3 The key action points in this strategy will also involve a wide range of partners, such as Carers Bucks, Public Health, and the Alcohol and Drugs Partnerships, in decisions about planning.
- 7.4 In order to evaluate progress in support for Buckinghamshire's carers over the next three years it is necessary to establish a baseline position as at 2015. These will include the ASCOF measures on:
- Per cent of carers who find it easy to find information about services
 - Per cent of carers included or consulted in the person they care for
 - Per cent of carers who have as much social contact as they would like
 - Overall satisfaction of carers with social services
 - Carer reported quality of life
 - Per cent of carers who receive Self-Directed Support and Direct Payments
- 7.5 For the duration of the strategy BCC intends to establish an' Implementation and Monitoring Group' to ensure that the key action points are being taken forward and achieving the outcomes identified. The Carers Partnership Board will oversee the implementation plan. Regular reports will be produced for the Adult Joint Care Commissioning Programme Board. There will be a further line of accountability to review the strategy by the Adult Joint Executive Team (JET) annually.

Commissioning action plan for carers

The action plan below is sectioned into the six key priority areas and will be implemented and overseen by a 'Carers Implementation Group'. The group will, through the actions below, strive to fully achieve the key principles and outcomes identified for our carers in Buckinghamshire.

Key Outcomes:

- A Support , value and recognise carers as equal partners in care**
- B Support and give carers confidence to have a life of their own outside of caring**
- C Involve carers in planning and shaping services**
- D Recognise that carers need flexible and responsive support**

Ref	Actions to be taken forward	Lead Professionals	Timescales	Key Outcomes to be Achieved
1. To Improve Identification Equality and Interface with Carers				
1.1	Continued emphasis on carer identification and recognition within GP practice in hospital and other settings: <ul style="list-style-type: none"> - BCC and CCGs to approach all relevant training and accreditation bodies to agree how they could integrate carer identification and awareness; - GPs to record more carers on the GP register to assist carers across information and support services. 	CCG Locality Managers	Year 1	Outcome A More carers were signposted to support other health and social care professionals
1.2	Promote consistency across the county with the early identification, intervention	BCC	Year 1	Outcome A, B

	<p>and support for carers to prevent unnecessary crisis, including a breakdown in carers' own health:</p> <ul style="list-style-type: none"> - Gain commitment from Prevention Matters and other voluntary organisations to identify carers and young adult carers in the hard to reach groups, including BAME carers through communities. - Understanding of the winter pressures on carers 	Commissioning Teams, Carers Bucks		Identified more 'hidden carers' and prevented carers reaching 'crisis point'
1.3	<p>Improve accessibility of services for carers, including rural areas such as the provision of short breaks, carer training, carer health and income:</p> <ul style="list-style-type: none"> - Carry out a mapping exercise to identify and target accessibility issues in the rural areas; - Identify critical pathway through the mapping of entry points to services; - Develop an information pack that is easy to follow, such as a flow chart for GP practices to easily navigate carers to appropriate services. 	BCC Commissioning, Carers Bucks, CCG Locality Managers	Year 2	Outcome A, D Improved accessibility to services for carers
1.4	<p>Buckinghamshire has many rural settings and in the north of the county transport links are a real issue:</p> <ul style="list-style-type: none"> - The local authority's transport strategies need to be designed to improve transportation in remote and rural areas is understood as to the implications it has on current guidance and the vision of this strategy. 	BCC Commissioning,	Year 2	Outcome D More carers accessed a range services across the county
1.5	<p>Review guidance continually and that any relevant changes to carers:</p> <ul style="list-style-type: none"> - Review the strategy in line with the development of the new National Strategy for Carers (January 2016) and the second part of Care Act 2017; - Ensure there is an understanding and focus on providing an economic case for investing in carers based on analysis carried out by Surrey County Council. 	BCC Commissioning,	Year 2	Outcome A, C Carers were involved and kept informed of new national developments that may impact on carers
1.6	<p>Carers should be involved, as appropriate, in the care plans for the people they care for and health and social care should involve the carer as much as possible in the care and treatment plan:</p> <ul style="list-style-type: none"> - Develop a 'whole family approach' pathway with health and social care taking into account all family members and other issues such as housing, income etc., this will 	BCC Commissioning, Carers Bucks, SUCO, CCGs	Year 1	Outcome A, C, D Carers were recognised as individuals and feel fully supported

	involve active listening and individual participation strategies from health and social care workers.			
1.7	<p>Involve carers in planning and commissioning of services:</p> <ul style="list-style-type: none"> - Ensure that carer participation is embedded in commissioning strategies, that involve carers in design and delivery of services; - BCC and partners to continue to promote and monitor the use of carer outcome evaluations and from this establish learning networks and promote good practices to BCC and CCG commissioning activities; - Carers Bucks and SUCO will seek to identify new and creative ways to improve carer involvement in all aspects of planning and shaping the delivery of care and support services. 	BCC Commissioning, Carers Bucks, SUCO, CCGs	Year 2	Outcome A Carers were fully engaged and improved outcomes delivered for carers across the county
1.8	<p>If any resources, support and services are not available to meet need, BCC will use the ASCOF¹⁶ measure and other initiatives to record activity data:</p> <ul style="list-style-type: none"> - To put in place specific improvement plans attached to the ASCOF performance with measurable actions and outcomes for each year; - To be reviewed annually and actions set for each year from April. 	BCC Commissioning,	Year 1	Outcome B, D Assisted with future strategic planning having identified gaps and improvements in carer services
1.9	<p>Increasing the recognition of carers in society, including the BAME and the diversity and demography of carers by professionals, ordinary people and organisations:</p> <ul style="list-style-type: none"> - Organise an event(s) to launch the 'Carers Strategy' countywide during Carers Week and as necessary throughout the lifetime of the strategy, as decided by the Carers Partnership Board. 	Carers Partnership Board	Year 1,2,3	Outcome A Encouraged more people to be aware of and support carers in their community and improved the social value of carers
1.10	Develop a process with wellbeing services that specifically market to hidden carers	BCC	Year 1	Outcome A, B

¹⁶ Adult Social Care Outcomes Framework

	<ul style="list-style-type: none"> - Work with Carers Bucks and other wellbeing services to identify those carers who are referred due to high levels of stress/anxiety. 	Commissioning, Carers Bucks		Increased number of known carers and reached out to more 'hidden carers' to ensure support is provided to them at the right time
1.11	<p>Improve the recognition of carers and support given at hospital discharge:</p> <ul style="list-style-type: none"> - Ensure that hospitals are equipped with relevant information that will support carers in their caring role, including working closely with the new Carers Hub at Stoke Mandeville - Evaluate the Carers Hub service for the potential of providing similar services in Amersham and Wycombe hospitals. 	Acute hospital discharge teams, Carers Bucks, CCGs	Year 1	Outcome A, B, D Improved numbers of carers supported through NHS
1.12	<p>Economic value of carer</p> <ul style="list-style-type: none"> - Analysis of the economic value of carers based on other local authority methodology and the new national strategy guidelines 2016/17 on invest to save 	BCC Commissioning and CCGs	Year 3	Outcome A, C Improved understanding of what works and effective invest to save models

2. To improve Information, Advice and Guidance (IAG) for Carers

2.1	<p>Review the carers pathway:</p> <ul style="list-style-type: none"> - Ensure that carers who do not receive a carer's assessment/plan are able to access good information, advice and support that is easily accessible and easy to navigate; - Ensure that the carer pathway and Carers Bucks keep a focus on the provision of timely, accurate and good quality information and advice not only when someone is new to caring, but whenever information and advice is needed; - This will include information to young adult carers. 	BCC Commissioning, Carers Bucks, CCGs Locality Managers	Year 1	Outcome A, B, D Carers accessed good information and advice at the right time, they received greater clarity of access for where and who to go to, particularly
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				out of hours
2.2	<p>Continue to improve information, advice and guidance for carers:</p> <ul style="list-style-type: none"> - Review and monitor IAG available to carers on the website as well as non-website information that is through GP practices, libraries and community centres; - Ensure the website includes 'Support for carers' section, providing general information and contact details for local services and support organisations; - Look at how to provide accurate information through a range of media, locations and organisations. 	BCC Commissioning, Carers Bucks,	Year 1	Outcome B, D IAG was kept updated and accurate for carers making IAG more easily accessible
2.3	<p>Early diagnosis of a condition, syndrome or illness helps would-be carers to access information and advice at the earliest opportunity:</p> <ul style="list-style-type: none"> - This approach should be embedded into NHS continuing healthcare, where carers needs are considered alongside the patient going on to receive care outside of the of hospital that is arranged and funded by the NHS 	GP practices, Acute hospital discharge teams	Year 1	Outcome A, B, D Carers accessed information early avoiding carers becoming anxious, feeling stressed, getting into crisis situations
2.4	<p>Improving better joined up information and consistency between professionals and provider organisations:</p> <ul style="list-style-type: none"> - Ensure that health and social care professionals, including GP practices are equipped and understand their key role in providing easy read information, such as a flowchart and advice to carers with greater clarity on where carers should go in a crisis; - Improve signposting and getting information for carers between health and social care professionals and other providers; - Promote IAG through libraries, carer support groups, Public Health and other representative organisations; - More information should be provided to carers on moving and handling, emergency first aid and end of life; - Work with Carers Bucks to include more staff, including those in GP practices, to be offered training in carer awareness, linking with Protected Learning (PLT) time 	BCC Commissioning, Carers Bucks, CCGs	Year 2	Outcome A, B, D More carers found it easier to navigate through a complex system and less carers felt confused and isolated; Professionals were better informed on IAG for carers

	for GPs.			
2.5	Improve accessible information for carers from Black, Asian and Minority Ethnic (BAME) communities: <ul style="list-style-type: none"> - Review the current IAG and improve on the information available to all BAME communities or for whom written English is not accessible 	BCC Commissioning, Carers Bucks	Year 1	Outcome A, B, D Improved the number of organisations receiving IAG so that it easily accessible to BAME communities

3. To improve the Range of Flexible Support

3.1	Support needs to be individualised and tailored to individual needs: <ul style="list-style-type: none"> - Review and monitor the type of support available to carers through monitoring the use of direct payments - Ensure carers needs are considered through self-directed support and that direct payments enable them to access a range of support at the right time in their caring role - Review and monitor the type of universal services being accessed through Carers Bucks 	BCC Commissioning, Carers Bucks	Year 2	Outcome D Improved the range of services available to carers through monitoring processes and having better understanding of services carers want to access
3.2	Ensure that other commissioning strategies specific to their service area or condition-specific identify and support carers in need in their strategic plans: <ul style="list-style-type: none"> - Review service area plans and ensure carers needs are considered and references are made to IAG and other support networks - Ensure that carers are involved with planning and shaping of future service area specific plans 	BCC Commissioning, CCGs	Year 1,2,3	Outcome B, C, D Improved the wider range of support for carers, particularly those in condition specific caring roles
3.3	Encourage and support the continued development of more effective ways of providing short breaks: <ul style="list-style-type: none"> - This will be through learning networks and, where possible, the setting up of 	BCC Commissioning, Carers Bucks,	Year 2	Outcome B, D Improved the chances of carers getting a short

	<p>demonstration projects and work with a range of organisations to explore the potential to develop short breaks provision through volunteers</p> <ul style="list-style-type: none"> - Explore the range of short breaks available, look at demand in services and develop plans for these services, such as sitting services for carers - Work with Carers Bucks and others to disseminate the findings of the short breaks research and to consider the development of further actions in light of the findings. In particular, to use the research findings to support partners to improve the local strategic planning and commissioning of short break provision. 	CCGs		break from their caring role and in turn improved their health and wellbeing
3.4	<p>Work with a range of organisations to explore the potential to develop respite and emergency respite and to support carers with emergency planning:</p> <ul style="list-style-type: none"> - Look to improve the quality and consistency of this information and statistics on respite services - Look at different models of respite and provision that can be easily accessible even at short notice and with a range of options. - Look at how carers can be better supported better through identifying unmet need and having local provision that meets the needs of carers and the people they care for 	BCC Commissioning, Carers Bucks,	Year 1, 2, 3	Outcome B, D Improved the range of respite provision across the county enabling carers to access such services easily
3.5	<p>Review the financial support services available to carers:</p> <ul style="list-style-type: none"> - Work with partners and voluntary organisations to promote financial inclusion for carers and services that are affordable to carers this includes looking at services available on the local borders 	BCC Commissioning,	Year 2	Outcome B Improved chances for carers to use their finances more effectively
3.7	<p>Improve the awareness and access to digital, assistive technology and equipment solutions for carers and the cared-for person:</p> <ul style="list-style-type: none"> - Ensuring that carers are aware and understand how digital, assistive technology and equipment solutions can assist with support for the people they care for and for themselves as carers 	BCC Commissioning,	Year 2	Outcome B, D Peace of mind, reduced stress and lessen the physical aspects of caring.
3.8	<p>Provide good quality support to carers who are caring for people with dementia, other condition-specific illnesses and end of life:</p>	BCC Commissioning,	Year 1	Outcome A, B, D Recognised and

	<ul style="list-style-type: none"> - Review the range of support available and look at demand and gaps for such services - Ensure specific actions plans include the support for carers 	CCGs		improved support for carers caring for specific needs
3.9	<p>Ensuring carers, especially the most vulnerable, are aware of the benefit of independent advocacy support:</p> <ul style="list-style-type: none"> - Ensure there is help for carers in many different ways, including supporting them in their dealings with health and social care and other professionals 	BCC Commissioning	Year 1	Outcome A, B, D Improved awareness of advocacy support to carers

4. To improve the health and wellbeing of carers

4.1	<p>Expand and improve access to psychological therapies for people of all ages as an alternative to drug treatments:</p> <ul style="list-style-type: none"> - This will benefit carers who need this type of support and who are concerned about the waiting times for such services - Enhance capacity and to train current NHS staff to deliver a range of evidence-based interventions 	CCGs	Year 2	Outcome A, B, Improved options for carers and the people they care for and giving them alternatives to traditional services
4.2	<p>Understanding and tackling the issues around loneliness and isolation for carers:</p> <ul style="list-style-type: none"> - Looking at ways to ensure carers maintain spontaneous life of their own and not feel left out - Work with other service areas to look at common issues and an action plan to take forward 	BCC Commissioning,	Year 2	Outcome B Improved the carers wellbeing and confidence by keeping them informed of keeping in touch with support networks
4.3	<p>Promote the benefits of the seasonal flu vaccine to carers:</p> <ul style="list-style-type: none"> - Work with public to ensure this is available to all carers and easily accessible 	BCC Commissioning, Public Health	Year 1	Outcome A, D Carers are protected from the effects of seasonal

				flu virus as well the people they care for
4.4	Support and provide information and data to the health inequalities project <ul style="list-style-type: none"> - Support the work of this project and take forward recommendations made through the final report in April 2016 	BCC Commissioning, CCGs	Year 2	Outcome B, C, D Key health inequalities Identified and appropriate action put in place to tackle the health inequalities faced by carers
4.5	Monitor and evaluate the number of carer health checks: <ul style="list-style-type: none"> - Work with Public Health to ensure that health checks to carers are easily accessible and improve on the uptake of these checks. 	BCC Commissioning, CCGs, Public Health	Year 2	Outcome B Improved the number of carers taking health checks to identify any health concerns early
4.6	Encourage partners to introduce programmes of training for carers on person-centred moving and handling and on the safe use of equipment <ul style="list-style-type: none"> - This should be linked to an assessment at the point of hospital discharge planning 	BCC Commissioning,	Year 2	Outcome B Carer kept safe through training
4.7	Continue to provide and raise awareness amongst both professionals and the carers of more bespoke services: <ul style="list-style-type: none"> - Produce information resource on issues relating to stress and caring - Continue to engage with carers to identify the need for services and ensure that a range of services are available to meet carers needs 	BCC Commissioning, Carer Bucks	Year 2	Outcome B, D Services already available to meet the needs of carers have had continued support and investment as necessary

4.8	<p>Paid carers need to be made aware of carers needs too, especially during induction training:</p> <ul style="list-style-type: none"> - Ensure that paid workers have positive relationships with carers and that training has been made available to all new care workers - Ensure that care professionals do not keep loading more onto the carers, adding further pressures - Improve the links and communications between health and social care professionals, so that carers are not having to repeat the same information 	BCC Commissioning, CCGs	Year 2	Outcome B Reduced the stress and pressures for carers dealing with paid carers care worker on a regular basis
	<p>Promote health and wellbeing courses and workshops:</p> <ul style="list-style-type: none"> - Identify with Carers Bucks and Public Health how carers can benefit from these and identify new courses as necessary with carers to be available to all carers across the county - Monitor the benefit of these on carers health and wellbeing 	BCC Commissioning, Public Health, Carers Bucks	Year 2	Outcome B, D Improved health and wellbeing of carers across the county and reduced stress from their caring role
4.9	<p>Raise local awareness and training in safeguarding issues in relation to carers for all stakeholders including carers.</p> <ul style="list-style-type: none"> - Work with the Safeguarding Board to ensure there is a better understanding and acknowledgement of the risk of significant harm to and from carers. This is critical to prevention. Awareness should be raised at all levels from management to operational staff on how abuse can arise, how to report and respond to it to it, when it does and to facilitate informed choice on how to minimise risk. - Ensure that carer pathways across the whole social care and healthcare system, including the independent sector, reflect and raise awareness of safeguarding issues and incorporate safeguarding strategies into support plans. - Review with carer organisations how they can work with carers on how to identify and manage risks of significant harm. Work with them to develop a culture where it is ok for carers to share their concerns around safeguarding and raise carer 	BCC Commissioning, Carers Bucks, CCGs, Carers Partnership Board	Year 1	Outcome A, B Improved understanding of safeguarding related to carers leading to improved identification of unintentional and intentional harm and reporting

	<p>awareness about the standard of care to be expected from service providers.</p> <ul style="list-style-type: none"> - Promote training of all stakeholders which recognises that carers can be both at risk of abuse and engage in abuse themselves - Review the prevalence of self-neglect amongst carers and work on measures to minimise this 			
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5. To improve employment and training opportunities for carers

5.1	<p>Encourage partners and the voluntary sector to promote ‘normalising’ carer employment practices in the workplace:</p> <ul style="list-style-type: none"> - Through identifying and building on good practice - Explore the opportunities afforded to carers in partnership with Job Centre Plus, to develop an ‘Integrated Employment and Skills’ service - Work with Carers Bucks and other carer organisations to build on good practice to identify the learning, career aspirations and employability requirements of carers - Promote corporate understanding of carers’ needs, particularly on work/life balance 	BCC Commissioning, Carer Bucks	Year 3	Outcome A Carers have equal choices as other employees and avoided carers feeling pressured or intimidated by employers
5.2	<p>Identify ways in which self-directed support can be more effectively targeted to help carers into training and employment:</p> <ul style="list-style-type: none"> - Work with other commissioning service areas to identify how this process can be utilised for carers 	BCC Commissioning,	Year 3	Outcome A,B, D Improved options for training and employment for carers
5.5	<p>More consideration needs to be given to e-training:</p> <ul style="list-style-type: none"> - Looking at ways to improve training availability for needs of carers in rural and remote locations 	BCC Commissioning, Carers Bucks	Year 3	Outcome B, D Improved access to carer services in rural areas
5.6	<p>Carrying out a full audit of carer and workforce training provision across the county:</p> <ul style="list-style-type: none"> - To get an accurate and up-to-date picture in order to enable a strategic view to be taken and to develop plans and funding requirements to address needs 	BCC Commissioning, Carers Bucks	Year 3	Outcome A, C Identified where the gaps are to improve workforce

	<ul style="list-style-type: none"> - Ensure carers pathway and support services are part of workforce training through staff induction training and continuous professional development, this could include good practice such as mandatory training module for health and social work staff and e-training for the workforce - Review existing training, education and learning modules for those working with carers and young adult carers and identify core competencies for NHS and social care staff 			understanding of carers
5.7	<p>Develop a carer training consortium:</p> <ul style="list-style-type: none"> - To support work at local level and to develop a quality assurance framework promoting high standards of training, with systematic carer outcome evaluation. - Using carers skills, knowledge for groups, education and training - Develop knowledge on condition-specific training for carers, such as positive behavior support for people caring for those with challenging behavior, dementia, and eating disorders; as well as therapy training such as attitudes and expectations, emotional health, mindfulness, talking therapies, assertiveness, etc. 	BCC Commissioning, Carers Bucks, CCGs	Year 3	Outcome B, C, D Use of existing skills and knowledge of carers and peer support

6. To improve services for young adult carers

6.1	<p>Need for collaboration between dedicated young carers' services:</p> <ul style="list-style-type: none"> - To get a broader awareness of the barriers to education, employment and training and to put in place relevant support to enable young adult carers to combine learning with caring - Explore ways in which referrals between young adult carers' services and Job Centres can be formalised and improved 	BCC Commissioning (Childrens and Adults)	Year 2	Outcome A, D Awareness of flexible, tailored learning opportunities
6.2	<p>Review and update previous IAG and publicity materials for young adult carers:</p> <ul style="list-style-type: none"> - To identify their options and the support available, in order to encourage young adult carers to achieve their career aspirations - Review and evaluate particular issues young adult carers face (including BAME young adult carers) when accessing education, employment and training - Design and develop materials focused on career management and employability and develop training opportunities for young adult carers' services 	BCC Commissioning, Cares Bucks (Adults and Childrens)	Year 1	Outcome B, D Improved the options available for career choices to young carers

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6.3	Continue to support local partnerships: <ul style="list-style-type: none"> - To deliver more choices and opportunities for young adult carers at risk of making poor lifestyle choices or becoming isolated or depressed 	BCC Commissioning (Adults and Childrens)	Year 2	Outcome A, B, D Improved young carers health and wellbeing by providing support at the appropriate time
6.4	Ensure parent carers are fully informed of policies and processes: <ul style="list-style-type: none"> - This should include help to understand the eligibility criteria, charging policy and services when their son/daughter is transitioning from children to adult services through the new transitions protocol 	BCC Commissioning (Childrens)	Year 3	Outcome B,C Improved communications with families, so that services continue during transitions
6.5	Improve working with mainstream children's service: <ul style="list-style-type: none"> - Ensure access to support is seamless through transitions for young carers as they move into adulthood. 	BCC Commissioning (Adults and Childrens)	Year 2	Outcome C Representation on Carers Partnership Board
6.6	Improve website and access through face book for safe support on internet and phone: <ul style="list-style-type: none"> - Work with BCC communications team and IAG leads 	BCC Commissioning (Adults and Childrens)	Year 2	Outcome A. D Monitored positive feedback and number of hits recorded to further improve IAG for young carers
6.7	Develop peer support: <ul style="list-style-type: none"> - Review work carried out by Carers Bucks and engage with young adult carers to develop new models of support networks, particularly for those who cannot access existing support 	BCC Commissioning, Carer Bucks (Adults and Childrens),	Year 1	Outcome B.C Improved the support networks for carers

Appendix One

The Adult Carers Survey was carried out in 2014. Of the 339 carers surveyed in Buckinghamshire. The key findings from the survey were:

- 44 per cent reported having no health issues.
- 66 per cent did not receive enough encouragement in their role, 16 per cent did not receive any at all.
- 75 per cent were not able to spend enough time as they would like doing things they valued and enjoyed, and 10 per cent said they were unable to do anything they valued or enjoyed.
- 66 per cent did not have enough control over their daily lives, and 12 per cent had no control. (This was most likely in the 45-85 age groups though this was also the largest group of respondents. Carers reporting that they did not have control were less likely to report being able to look after themselves).
- 16 per cent of carers reported that they were neglecting themselves in terms of sleeping and eating well. None of these respondents indicated that they had control over their daily lives.
- 13 per cent felt socially isolated and 48 per cent reported not having enough social contact.

Recognition and motivation to improve wellbeing, and the impact of poor wellbeing on carer role:

- Carers UK interviewed carers post-breakdown and found significantly higher levels of depression and anxiety than carers coping. They were less likely to be able to leave the house.
- One in four carers had needed medical treatment as a result of their breakdown. Carers responding to the survey reported serious health problems such as heart attacks and hernias.

Wider factors influencing the wellbeing of the carer:

- The condition of the person they are caring for (for example if they have a poor relationship with the person; if the person's condition is deteriorating; or has significantly altered their personality e.g. if they have a brain injury)
- Breakdown can force carers to make sudden decisions, such as quitting work or university, or purchasing expensive care. This can lead to further strain.
- BME carers found difficulties in accessing health and social care, and experienced related issues such as stigma, language barriers, stereotypes and assumptions.
- The age of the carer – 25 per cent of carers aged 35-44 reported feeling socially isolated as did 21 per cent of carers aged between 45 and 54. Carers aged 85+ were the least likely to feel socially isolated.

Appendix Two

The recent Buckinghamshire Carers Needs Analysis 2015¹⁷ shows the impact of caring on carers and the factors influencing this impact:

Physical health

The impact on a carers physical health was reported as getting older, sleep deprivation, exhaustion, musculoskeletal problems and deterioration/ neglecting own health. (Buckinghamshire Adult Carers Workshops 2015). Factors influencing this impact were:

- Barrier to participating in health protective behaviors: adult carers don't prioritize their own health; carers need to continue caring even when ill and lack of time to focus on maintaining own health and wellbeing. (Buckinghamshire Adult Carers Workshops);
- GP records of male carers compared to non-carers shows the prevalence is 54 per cent higher for stroke and 50 per cent higher for type 2 diabetes. In female carers compared to non-carers the prevalence is 40 per cent higher for ischemic heart disease – this is similar to male carers where the prevalence is also 40 per cent higher compared to non-carers. (GP EMIS Data–AVCCG);
- The influenza vaccine uptake rate in Buckinghamshire CCGs for the carers risk group is the lowest when compared to other adult at-risk groups in Buckinghamshire CCGs.

Mental health

The main mental health issues raised by carers were anxiety, stress, low mood and emotional exhaustion. (Buckinghamshire Adult Carers Workshops 2015). Factors influencing this impact were:

- Causes of poor mental health in carers were highlighted: lack of emergency plans in place, coping with change, always on call, guilt and practical impact of caring on life and social freedom. (Buckinghamshire Adult Carers Workshops);
- Caring for those with mental health issues can be stressful particularly for young carers. (Local Stakeholder Interviews);

¹⁷ Public Health Needs Analysis on Carers Summary Report 2015

- Emotional wellbeing of young carers at assessment: 83 per cent of young carers experience anger (all the time or sometimes) and 80 per cent of young carers feel stressed/fed-up (all the time or sometimes). (Young Carers Assessments);
- GP records show anxiety states 72 per cent higher in female carers compared to non-carers. In male carers the prevalence is nearly doubled for anxiety states and depressive disorders compared to non-carers.

Employment

In Buckinghamshire 38.4 per cent of carers are economically inactive. This is better than six of its 10 closest statistical neighbours. It is also better than the economic inactivity among carers in the South East (40.8 per cent) and nationally (42.3 per cent). (ONS Census 2011). The factors influencing the impact on employment were:

- Lack of awareness of rights amongst carers; reluctance to inform employer; provision for greater support from employers. (Local Stakeholder Interviews 2015);
- When asked about working while being a carer it appears that 17.9 per cent are unable to take up paid employment due to caring. (HSCIC Adult Carers Survey 2012-13);
- Carers report added pressure and being unable to cope with work and caring duties. However, the impact of caring on employment varies: some having to give up work, others noting a decline in performance and others being able to adapt work to suit caring responsibilities. (Buckinghamshire Adult Carers Workshops 2015)

Education

The main difficulties young adult carers reported with education was difficulty in concentrating (60 per cent all the time or sometimes) and being late for school or college (53 per cent all the time or sometimes). Only 17 per cent of young adult carers report they “sometimes” plan for the future. (Young Carers Assessments)

Finances

There are many self-funders in Buckinghamshire. Self-funding for care can have a significant financial impact over time and working carers face a dual hit - reduced income and increased expenses. (Local Stakeholder Interviews 2015). Factors influencing this impact were:

- Some financial issues impacting carers include: financial difficulties; high cost of care providers; and out of pocket expenditure. (Buckinghamshire Adult Carers Workshops 2015);
- Financial difficulties are exacerbated by: lack of information and issues regarding the process of benefits to which carers are entitled. (Local Stakeholder Interviews 2015);
- Impact of caring: relationships with others;
- Relationships with friends being impacted is commonly reported. This is due to: time constraints; friends becoming distant and being unable to relate; caring dominating life and emotional (e.g. feeling guilty) and practical constraints of their caring role. (Buckinghamshire Adult Carers Workshops 2015).

Relationships with family

Carers reported that relationships with families were often affected as distant family members do not realise the extent of caring duties and their impact, carers isolate themselves, mobile younger family members are not near enough to help and caring places a strain on the relationship with other family members. (Buckinghamshire Adult Carers Workshops 2015). Factors influencing this impact were:

- Adult carers primarily plan on relying on family (six in 10 carers) in an emergency. (Adult Carers Assessments);
- The most common social impact reported by young carers is difficulty participating in family or social activities (63 per cent all the time or sometimes). 40 per cent of young carers all the time or sometimes report difficulty making friends. (Young Carers Assessments);
- Caring has an impact on the relationship with the cared-for: mostly this relationship is viewed positively but some have noted that the relationship changes as one becomes a carer and occasionally it can be a difficult or demanding relationship with cared-for. Nearly seven in 10 young carers provide comfort to those they care for - the most common type of emotional support given. (Adult Carers Assessments).

Impact of caring: social freedom and isolation

Only a fifth of carers feel they have control over how they can spend their spare time. Furthermore, only approximately a quarter of carers feel they have as much control over their life as they wish. (HSCIC Adult Carers Survey 2012-13). In Buckinghamshire Carers reported that they feel lonely even if not alone. 1 in 10

carers feeling particularly socially isolated. (Buckinghamshire Adult Carers Workshops 2015). Factors influencing this impact were:

- Loss of relationship with cared-for, who may have been a significant part of their social interactions, when one spouse becomes a carer particularly for someone with a condition such as dementia. (Local Stakeholder Interviews);
- Social isolation is a problem for carers when their caring role ends as they lose their carer support networks and have a lot more spare time. (Stakeholder Interviews);
- 77 per cent of carers report some impact of caring on being able to socialise. When reviewing 100 carers assessments there were:
 - 32 mentions of carers feeling restricted by caring - lack of freedom and control over one's life,
 - 30 mentions of practical difficulties to socialisation
 - 18 mentions of not having a break from caring. (Adult Carers Assessments).

Social value

Many carers have said they feel there is a lack of recognition of unpaid carers by society and professionals. Professionals appear to only recognise or know of formally paid carers. (Local Stakeholder Interviews 2015). Factors influencing this impact were:

- The vast majority of carers have experienced some lack in encouragement (46.4 per cent). (HSCIC Adult Carers Survey 2012-13);
- 65.7 per cent (95 per cent CI: 60.8-70.6 per cent) of adult carers feel included or consulted in decisions. This is significantly lower than the national (95 per cent CI: 72.5-73.3 per cent), South East (95 per cent CI: 72.8–75 per cent and similar local authorities (72.4 per cent). (HSCIC ASCOF data)

Smoking and Alcohol

A comparison between caring and non-caring resident in Bucks found that both male and female carers reported higher rates of smoking and unhealthy levels of drinking. Findings showed lack of motivation to quit smoking and lack of awareness of impact on the body, as well as societal factors influencing smoking – stress, illness, and culture and class background.

Factors influencing drinking were: carers are extremely vulnerable to stress, depression, anxiety and social isolation, all of which may lead to self-medication with alcohol. In the UK, excessive drinking is more common in people backgrounds, and

people from higher socio-economic areas. Other factors included access to and experience of support with alcohol moderation/cessation. This would include broad advice apart from support with alcohol addiction.

Physical activity and health eating

In terms of physical activity and healthy eating, obesity in Buckinghamshire is 2.15 times higher for female carers than for female non-carers, and 2.6 times higher for male carers than for male non-carers. This was because many of the carers reported that they were unable to exercise. Other factors also included having to cut back on food to save money and not being able to find the time to eat, as well as factors such as stress, depression, and being forced to put the cared-for person's needs first.

Wellbeing

Wellbeing among carers is reported to be very low. Of the 100 adult carers in Buckinghamshire surveyed for the carers' needs assessment:

- 77 per cent said caring had impacted their social life.
- 31 per cent had seen it impact relationships with others.
- 53 per cent said it had impacted their mental health
- 23 said they had a difficult relationship with the person they cared for.
- 18 mentioned having no break from caring.

The needs analysis also highlighted that in 2014, there were 3,699 carers known in Buckinghamshire to the county council. However, there were 49,500 people who were self-identified as carers in Buckinghamshire (census 2011), which means potentially 95 per cent of carers were classed as 'Hidden' carers in 2011.

The characteristics identified for a 'hidden carer' for Buckinghamshire included:

- Carers providing less than 50 hours/week of care are more likely to be 'hidden' carers.
- Carers under the age of 65 are more likely to be 'hidden'.
- Hidden carers are likely to exist in all communities. Ethnic minority carers are more likely to be 'hidden'.
- Men are more likely to be 'hidden carers' than women.
- Carers are more likely to be around urban hotspots. Higher proportion of carers in the north of the county might be hidden.

Factors influencing 'hidden' carers in Buckinghamshire are:

- Increase in proportion of carers in the total population (particularly those providing care more than 50 hours/week). In Buckinghamshire the percentage

change in proportion of carers in the population from 2001 to 2011 was 7.1 per cent (absolute proportion increase from 9.15 per cent to 9.8 per cent).

- More carers are coming forward to be registered as carers with the council particularly in recent years. In 2001 0.07 per cent of the carer population was registered with BCC but in 2011 4.79 per cent of the carer population was registered.
- Nearly 70,000 local carers are predicted in 2037. A significant increase in older carers is expected.
- Increase in demand for services above the expected rate due to the CARE ACT 2014.