

Bristol Carers Strategy Refresh

2015 – 2020

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Executive Summary

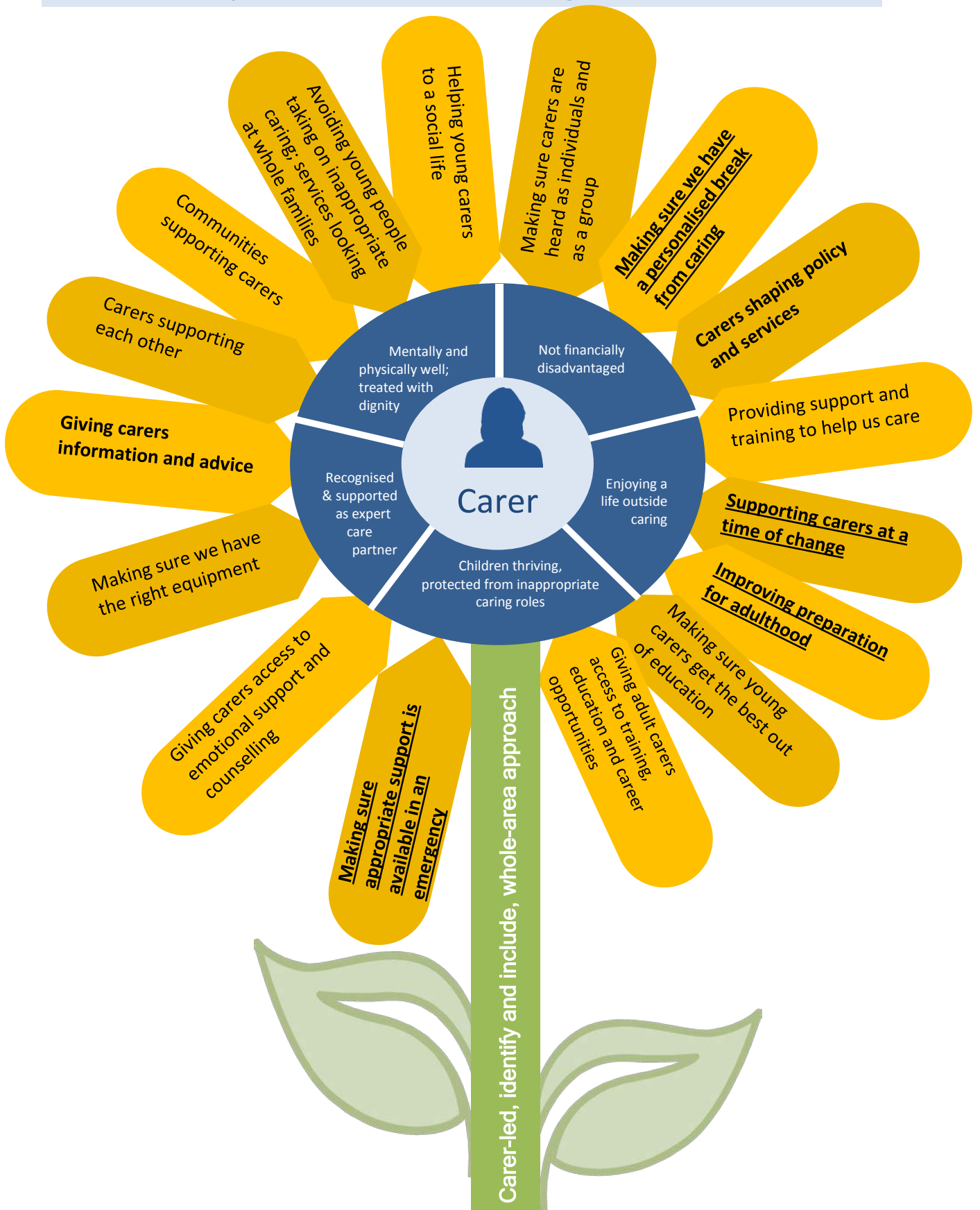
- This joint strategy has been co-produced by Carers, Bristol City Council, Bristol Clinical Commissioning Group ('CCG': NHS), and voluntary sector organisations that provide services for or have an interest in carers
- The strategy covers the whole of Bristol and is written for all carers so includes adult carers, young carers, young adult carers, sibling carers and parent carers
- The purpose of the strategy is to outline Bristol's vision and outcomes for carers, which is based on the National Carers Strategy:
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 of caring, while enabling the person they support to be a full and equal citizen.

Additionally, Bristol carers suggested the following overarching statements to set the vision for Bristol

- Achieving change for carers means listening to them and ensuring their voices are heard by decision makers on service design
 - Bristol needs to take a 'whole area approach' recognising that a huge range of services need carer-awareness and training for their staff
 - The successful development of interventions that benefit carers relies on the presence of services that identify and include carers, in order that those most at risk of being overlooked and isolated can benefit
- The strategy outlines 3 main areas of work to achieve those outcomes:
 1. Targeting specific groups
 - Carers from black and minority ethnic communities
 - Young carers and young adult carers
 - Carers of people with mental ill health
 - Carers of people with dementia
 2. Implementing the Care Act and the Children & Families Act
 3. Four specific areas to focus on
 - Personalised breaks from caring
 - Support for carers at times of change, including preparation for adulthood and end of life
 - Appropriate support in an emergency

- Information and advice, including benefits and financial issues
- The strategy will be implemented through an action plan, developed by partners including carers, and the plan will be overseen by the Carers Strategy Implementation Group (CSIG)

Executive Summary: Carers' Priorities Sunflower Diagram



Introduction

This is a joint strategy which has been co-produced by Carers, Bristol City Council, Bristol Clinical Commissioning Group (NHS), and voluntary sector organisations that provide services for or have an interest in carers.

Scope of this Strategy

The strategy covers the whole of Bristol and is written for all carers so includes **adult carers, young adult carers, young carers** and **parent carers**.

This strategy will be implemented through an action plan, to be developed with partners, including carers, and the plan will be overseen by the Carers Strategy Implementation Group (CSIG).

Why Carers Matter?

It's very simple to explain why carers matter.

There are lots of carers. 1 in 10 of us is a carer. According to the 2011 Census 40,100 carers live in Bristol, 9000 of those provide more than 50 hours of care a week. Other research suggests that there could be up to 7,600 further young carers in Bristol (source: Bristol Carers Support Centre, using Becker and Dearden formula, Loughborough University, based on ONS mid-2014 population estimates).

Carers save the Government money. Many carers support people who would otherwise need statutory services, therefore saving the NHS and Local Authorities money. The economic value of the contribution made by carers in the UK is £119bn per year¹.

Caring often impacts negatively on health and wellbeing. Caring for a loved one who is ill can take a serious toll on the carers' mental and physical health, their personal relationships and family finances, the educational attainment of young carers, and we know that being a carer is a key factor which can lead to social isolation. According to recent research by Carers UK (2014)²:

- 6 in 10 carers have been pushed to breaking point
- A quarter of those who had reached breaking point required medical treatment as a result
- 46% of carers said they had fallen ill but just had to continue caring
- 1 in 9 said the person they cared for had to be rushed into hospital, emergency care or that social services had to step in to look after them while the carer recovered

¹ <http://www.carers.org/key-facts-about-carers>

² <http://www.carersuk.org/for-professionals/policy/policy-library/carers-at-breaking-point-report>

- 1 in 5 were forced to give up their jobs because they were in crises

There will be more carers in the future. The number of carers is set to increase as people are living longer with disabilities and long term health conditions. The pressure on families to care in their own homes, particularly for spouses and partners, is growing significantly and is predicted to double in the next 30 years³.

Carers need and have a right to be supported in their caring role. Carers are entitled to a Carers Assessment, information, support and advice in law. These rights need to be upheld.

Definition of a carer

A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health issue or an addiction cannot cope without their support. Carers can provide physical or practical care and/or emotional support to somebody in, for example, their own home, supported living, care homes or psychiatric wards. The definition covers 'caring for somebody' and 'caring about somebody'; both are important caring roles.

A carer could be a spouse, partner, parent, sibling, child (usually referred to as a 'young carer'), friend or any other relation. Anybody from any background and of any age can be a carer and each carer's experience is unique to their own circumstances. The causes of someone taking on caring responsibilities are varied but can include:

³ <http://www.pssru.ac.uk/archive/pdf/dp2515.pdf>

- Long-term condition
- Physical disability
- Long-term neurological conditions
- Mental health issue
- Dementia
- Addiction/substance misuse
- Learning disability

Just as the reasons why someone becomes a carer vary greatly, the variety of tasks that a carer fulfils is diverse. They can include any of the following: **practical tasks** such as cooking, cleaning, washing up, ironing, paying bills, financial management and engaging appropriate services; **personal care** such as bathing, dressing, lifting, administering medication and collecting prescriptions; and **emotional support** such as listening, advocacy, problem solving, motivating and companionship.

Our definition of a carer *does not* include people who are employed to provide care e.g. care workers, home care staff, district nurses, foster carers and people who work in an unpaid capacity for a voluntary organisation.

National Picture

According to the 2011 Census⁴, there were approximately 5.8 million people providing unpaid care in England and Wales in 2011, representing just over one tenth (10.3%) of the population. The absolute number of unpaid carers has grown by 600,000 since 2001; the largest growth was in the highest unpaid care category, those who provide unpaid care for fifty or more hours per week.

There are national laws and guidance from the Government that set out how Local Authorities and the NHS should be supporting carers. A summary of these is found at Annex A and B; this strategy will be based in the context of these. Of most significance are the **Care Act 2014**, the **Children and Families Act 2014**, and the **National Carers Strategy refresh 2014 (Department of Health)**.

Local Picture

Carers in Bristol

According to the 2011 Census, there are over 40,100 carers in Bristol (all ages), which is just under 1 in 10 of the population (9.4%). Over the last decade (since 2001 Census) the number of unpaid carers recorded has increased by 5,000, but the proportion stayed the same (9.3% in 2001) as Bristol's population has risen considerably. The majority of adult carers (25,700) are caring under 20 hours a week but just over 9,000 are providing unpaid care for 50 hours or more each week.

Of the 40,100 unpaid carers identified in the 2011 Census, 860 were children under 16 and 2,700 were young people aged 16-24. There are also 8,300 carers who are over 65 years of

⁴ <http://www.ons.gov.uk/ons/rel/census/2011-census-analysis/provision-of-unpaid-care-in-england-and-wales--2011/art-provision-of-unpaid-care.html#tab-National-comparisons>

age (15% of all people over 65 in Bristol), and 40% of people in this age category (3,350 people) provide care for over 50 hours a week, which is disproportionately high.

Young Carers

It is estimated that there are more young carers in Bristol than identified in the Census as young carers are a largely hidden group of carers and may not be recognised within the family where they have caring responsibilities, or even identify themselves in that role.

We use other local data to estimate that there are currently 7,600 young carers in Bristol (source: Bristol Carers Support Centre, using Becker and Dearden formula, Loughborough University, based on ONS mid-2014 population estimates).

This uses a more informal definition than the 2011 Census, and is updated more regularly. It includes, for example, information from schools.

The majority of young carers have been caring for between 3-5 years (3,392) and 2,775 have been caring for 2 years or less. 82% of young carers in Bristol (6,321) are providing emotional support and supervision and 18% (1388) are carrying out personal care.

It is not possible to simply add the local figures we have on young carers to the national Census data to arrive at a 'total number of carers' as this will result in some double counting.

Caring and working in Bristol

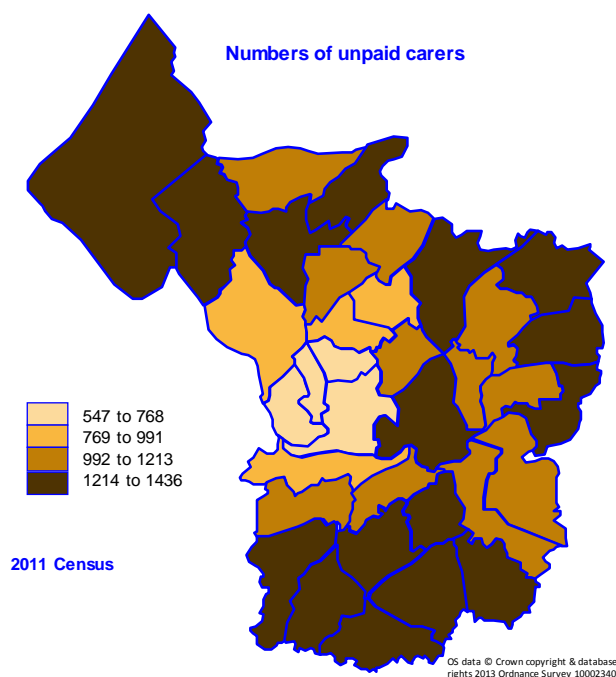
75% of carers in Bristol are considered working age (18-64 years) and 66% of carers combine work and their caring role. Over 4,000 carers in Bristol are working and caring for 50 hours or more each week. (2011 Census).

Carers' health

Overall, only 5.5% of all people in Bristol said they had bad or very bad health (similar to national average of 5.6%, 2011 Census). For people with caring responsibilities though, this rises to 7.8% of all carers in Bristol having bad or very bad health themselves, and 14.9% of people who provide unpaid care for over 50 hours a week.

Carers across Bristol

Overall, there are more people with caring responsibilities in Bristol's outer wards than in more central areas, and more in South Bristol. Other than Hillfields (North East Bristol) and Lawrence Hill (Inner City), 5 of the 7 highest



wards for numbers of unpaid carers are in outer South Bristol.

Ethnic profile of carers in Bristol (using 2011 Census figures)

- White: 35,450 (88.3%)
- Mixed ethnicity: 800 (2%)
- Asian or Asian British: 1,700 (4.2%)
- Black or Black British: 1,900 (4.8%)
- Chinese or other ethnic group: 250 (0.6%)

Local Policies and Strategies

This strategy has been co-produced with carers, it builds on the previous ***Joint Carers' Strategy 2008-2011***, and the achievements made with carers so far: see Annex D ***Celebrating achievements: we made it happen for carers 2014***. It also builds on the previous ***draft Multi-agency partnership strategy for young carers 2012-2015***, and is developed in the in the context of the following local strategic plans:

Bristol Health and Wellbeing Board Priorities

The Mayor's *Vision for Bristol* reflects a clear commitment to being a healthy, caring city and includes an acknowledgement of the key role carers play in the City.

The main purpose of the Health & Wellbeing Board is to join-up commissioning and services across the NHS, social care, public health and the voluntary sector, to benefit people's health and wellbeing. The Bristol Health and Wellbeing Board approved the ***Joint Health and Wellbeing Strategy*** in autumn 2013, which identifies the overarching health themes for Bristol; that it is a city:

- Filled with healthy, safe and sustainable communities and places
- Where health and well-being are improving
- Where health inequalities are reducing
- Where people get high quality support when and where they need it

The strategy prioritises young carers and carers of people with Dementia. Another relevant priority set by the Health and Wellbeing Board is tackling social Isolation.

Bristol City Council's Corporate Plan 2014-2017

A 'Healthy and Caring' Bristol is identified as one of nine key themes within the plan. The aspiration is that 'Bristol will be a place where the cared for and the caring, young and old, are respected and valued members of our society; and where healthy, happy and safe lives and homes are shared aspirations for every citizen'.

Supporting Carers Through Change Protocol

This protocol has been co-produced by Carer Representatives, Bristol City Council Health and Social Care, and the Bristol Carers Support Centre. It aims to provide a useful toolkit for

those professionals within Bristol involved in overseeing a change in service, when any major change or closure of a service is planned, for example the closure of a day centre, residential home, or changes in a day service. Its use ensures that carers are taken into account, are supported, involved and can work in partnership with professionals throughout the change.

Living Well With Dementia in Bristol, 2011-2015

A joint NHS Bristol and Bristol City Council commissioning strategy, setting out short, mid, and long-term priorities for future services for people with dementia and their carers. Key principles include:

- improve the quality of life for people living with dementia, and their family/carers
- recognise the needs of carers, as well as the important role they play and the expertise they have

Within the strategy, which sits alongside the Bristol Carers Strategy, there are seven focus areas identified, including:

- focus on improving the skills and competencies of all staff who work with people with dementia and their carers
- address the specific needs of people with dementia and a learning difficulty and their carers

Clinical Commissioning Group Strategic Priorities: Five Year Strategy 2014-2019

This sets out the CCG's strategic priorities with a vision for 'Better Health and Sustainable Healthcare for Bristol'. The vision and strategic priorities were developed in line with the Health and Wellbeing Board's overarching health themes for Bristol.

Feedback from carers, including young and parent carers, about local health services is a key building block in developing all CCG commissioning plans and **carers support** has been highlighted as a key priority for 2015/16. The CCG has jointly, with Bristol City Council, funded Bristol Parent Carers Network to support participation and engagement of parents who have disabled children, their involvement in service redesign, commissioning and delivery. Funding is initially from April 2014-March 2017.

This carers work, carers breaks and the implementation of the elements of The Bristol Carers Strategy for which the CCG is co-responsible, will move in to the Better Care Bristol Programme in 2015-16. This is a positive step as will ensure carers' support remains a priority. (For more information about Better Care Bristol please see the section with the same subheading on the following page).

University Hospitals Bristol (UHB) Carers Strategy 2013-2016: Carers As Partners In Care

The statement of strategic intent states:

'The trust Board of Directors is committed to ensuring that the University Hospitals Bristol

NHS Foundation Trust is an organisation which works in partnership with carers to ensure that patients receive safe, effective and compassionate care’.

North Bristol Trust (NBT) Carers Strategy 2015-2017

The statement of strategic intent states:

‘North Bristol Trust aim to ensure that all carers who either use NBT services or whom are a member of staff are recognised and supported appropriately. NBT also value the contribution of the carers in support of the cared for person in the planning and delivery of care’.

Both the UHB and the NBT Carers Strategies have accompanying Carers Action Plans which identify four main outcomes:

- All Carers who want to be are identified at UBH/NBT
- Carers who are identified at UHB receive information and support whilst they or the person they care for are in hospital and through the discharge process
- Carers are acknowledged, represented and involved at strategic level at UHB
- There is increased staff awareness, knowledge and expertise of carers and their needs

The UHB and NBT are developing a joint carers reference group, representing carers across both trusts, whilst reporting back specific issues to the relevant trust.

Hospitals Joint Carers Charter

Continuing the co-operative working between trusts, NBT and UHB have developed a Joint Carers Charter that recognises and clarifies a common purpose in:

- Recognising and valuing carers as equal partners, including young carers, parent carers and adult carers
- Supporting carers by providing information and support, including carers’ rights
- Sharing information, with patients consent
- Inclusion in discharge planning

Better Care Bristol (previously known as The Better Care Fund Programme)

The Council and the CCG are working in partnership with University Hospitals Bristol NHS Foundation Trust and North Bristol NHS Trust as well as community providers, Bristol Community Health, the Avon and Wiltshire Mental Health Partnership (NHS) Trust and Healthwatch Bristol to realise the ambition of Better Care Bristol to see ‘A city where people live happier and healthier lives and their care and support needs are met at the right time, to the right quality and in the right place for them’.

The Better Care Programme Board is providing the partnership working and oversight to deliver system transformation between health and social care, including:

- Greater integration of services, including rehabilitation and reablement
- Single point of access for health and social care for citizens of Bristol
- Social prescribing: referral to wellbeing services and peer support services

- Personalisation of services
- Development of a frailty pathway to support care closer to home
- A jointly commissioned information and advice service

Bristol CCG and Bristol City Council contribute towards a pooled budget, (previously referred to as the 'Better Care Fund') in order to jointly provide support for carers. This funding arrangement is helping to drive integration, partnership working and service transformation and includes funding for carer's breaks as one of the nine 'schemes' within the programme of work. A key principle guiding all investment by Better Care is to put patients, service users and carers at the heart of their planning.

Bristol Mental Health (BMH) Strategy

Bristol Mental Health is the new Bristol model of NHS-funded mental health care, delivered by a mix of public and voluntary sector organisations. A system leadership team has been put in place to make sure that the organisations work well together, and that there are no gaps in services. BMH is committed to the involvement of both service users and carers in their care, and the development and delivery of services. As such a key member of the system leadership team is 'Strategic Leader for Service Users and Carers', and is also a champion for service users and carers across all service provider organisations, and within BMH.

Bristol's Vision and Outcomes for Carers

Bristol's vision for carers is based on the National Carers Strategy:

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 of caring, while enabling the person they support to be a full and equal citizen.

Additionally, Bristol carers suggested the following overarching statements to set the vision for Bristol

- Achieving change for carers means listening to them and ensuring their voices are heard by decision makers on service design
- Bristol needs to take a 'whole area approach' recognising that a huge range of services need carer-awareness and training for their staff
- The successful development of interventions that benefit carers relies on the presence of services that identify and include carers, in order that those most at risk of being overlooked and isolated can benefit

Outcomes we want to see for carers in Bristol

Bristol carers, the NHS and Bristol City Council agree with the outcomes set out in the refreshed **National Carers Strategy**, which states that by 2018 every carer should be:

1. Recognised and supported
2. Enjoying a life outside caring
3. Not financially disadvantaged
4. Mentally and physically as well as they can be
5. (if a young carer) thriving and protected from inappropriate caring roles
6. Treated with dignity

How to achieve these outcomes

In order to achieve these outcomes for carers in Bristol, and in line with the whole area approach, many services, interventions and organisations will need to identify and work with carers.

Below is a list of interventions or activities that are necessary to achieve the six outcomes for Bristol carers. Carers in Bristol prioritised four of the interventions to look at over the next five years (in bold below) and these are set out with more detail in the priorities section below.

Interventions and activities required to achieve the carers' outcomes in Bristol:

- Activities for carers
- Advocacy for carers
- **Personalised breaks from caring**
- Supporting young carers to have a social life
- Brokerage and support for carers
- Carers shape policy and services
- Support and training for carers to help them in their role
- **Support for carers at times of change, including preparation for adulthood and end of life**
- Supporting carers to get the best out of education and training opportunities
- **Appropriate support in an emergency**
- Emotional support and counselling for carers
- Recognition and support for carers in the NHS
- Housing support, including adaptations and equipment
- **Information and advice, including on benefits and financial issues**
- Peer and community support
- Whole family support
- Supporting carers to work and access training

The interventions above are based on work carried out by the Carers Trust, a national organisation supporting carers and carer organisations across the UK. They were discussed,

adapted and agreed by carers in Bristol during 2014-15. Annex C, *Aims and Priorities of the Carers Strategy*, provides more detail and provides examples of services or interventions that fall under each one; it is expected that this table will form the basis of the Carers Strategy Action Plan.

Many of the interventions and activities are already available in Bristol; some require more action, other work needs to simply be continued.

Priorities for 2015 - 2020

To focus our work over the next 5 years, we have identified three areas for prioritising work with carers in Bristol;

1. Targeting specific groups of carers;
2. Implementing the Care Act and Children and Families Act and;
3. Four specific aims to focus on

More information on each is given below.

1. Targeting specific groups of carers

Bristol will focus on identifying and supporting the following groups of carers:

- Carers from black and minority ethnic communities
- Young carers and young adult carers
- Carers of people with mental ill health
- Carers of people with dementia

This means, activities that are coordinated under this strategy, should have a focus on these groups where appropriate. It is important to note that this prioritisation does not mean that other carers should not be identified and supported through the work of the strategy.

Carers from black and minority ethnic communities

Carers from black and minority ethnic communities generally have a lower uptake of carer assessments and a lower incidence of accessing services. Sometimes they can face additional challenges if English is not their first language and if there are cultural needs that are not being acknowledged. Statutory and other services need to work closely with community groups which often provide direct and culturally appropriate support services to carers.

Young and young adult carers

Young carers are now recognised in the Children and Families Act 2014 and the term refers to carers under 18 years old. Young adult carers are identified as being between 18 and 24

years old. Young and young adult carers are often hidden and need additional support during times of change.

Having to take on responsibilities that would normally fall to an adult - like providing intimate care, managing a home, or undertaking child care – can cause social isolation and lead to a young person experiencing mental health difficulties such as depression and stress. In recent research into young carers in Edinburgh, it was found that 67% worried about their own health, 60% had problems sleeping and 30% problems eating and, most worryingly, over 30% had self-harmed or had had suicidal thoughts (See <http://www.scotland.gov.uk/Publications/2010/07/23153304/42>)

In their 2013 report, *Hidden from View*, the Children's Society stated that the official figures were just the 'tip of the iceberg' due to the high volume of 'hidden carers' who do not access support. Among the findings of Hidden from View were:

- Young carers are one and half times more likely to have a special educational need or a long-standing illness or disability
- Around one in 20 miss school because of their caring responsibilities
- Young carers have significantly lower educational attainment at GCSE level - the equivalent to nine grades lower overall than their peers
- Young carers are more than one-and-a-half times as likely to be from black, Asian or minority ethnic communities, and are twice as likely to not speak English as their first language
- The average annual income for families with a young carer is £5,000 less than families who do not have a young carer
- Young carers are more likely than the national average to be 'not in education, employment or training' (NEET) between the ages of 16 and 19
- Despite improved awareness of the needs of young carers, there is no strong evidence that young carers are any more likely than their peers to come into contact with support agencies

Young carers

For children under the age of 18, carrying out caring responsibilities can have a huge impact on a young person's education, social life, physical and emotional development. This can severely affect their future career and life options.

- Many children and young people do not see themselves as carers. They just see themselves as supporting (usually) a family member and doing what anyone else would do in their situation, particularly if the parent or sibling has mental health or drug and alcohol misuse problems.
- The parent(s) themselves often do not recognize either that they have a problem or that the care they receive from a young person may be inappropriate and have an adverse effect on the outcomes for this young person.

- Many young carers struggle with social inclusion, including isolation, bullying and mental ill health including depression, anxiety and self-harm.
- Many young carers have fewer opportunities to access time out from caring, and limited access to provisions for a break due to their family circumstances.

It is therefore paramount that professionals have an awareness and understanding of young carers in order to identify and offer support.

Young adult carers

Young adult carers have frequently been overlooked and services have not met their needs. Under the Care Act 2014 'young adult carers' have been recognised as an identified group.

Many young adult carers have already been affected by their responsibilities as young carers, however in addition

- Young adults are at important, transitional stages of their lives, and may not have the same opportunities or support during, for example, leaving home, going to university, entering employment.
- They are often juggling too many situations and put their own needs last which can have a detrimental effect on both their own mental and physical wellbeing.
- Early transitional support is vital to identify all needs and holistic support for the cared for

During the Young Carers Voice Residential weekend April 2013, **Bristol young carers identified that they want:**

Staff to:

- Be approachable, understanding and trustworthy
- Have a knowledge of young carers issues
- Have more time for us to have one to one with them

To have from their services:

- Someone to talk to
- An opportunity to meet other carers
- To be free of charge
- Support with transport or reduced or free bus travel
- Have different times for different age groups
- Have different kinds of activities
- Have a break, especially in school holidays

Schools to:

- Have designated staff to support young carers
- Have teachers that are non-judgemental
- Have teachers that have an understanding of young carers issues

Carers of people with mental ill health

Mental health carers are less likely to disclose their caring role because of the stigma of mental illness, and may feel unable to talk about their experience with friends. This can be an added barrier for BME carers. There are additional barriers for mental health carers that make them a priority group:

- Staff members and carers themselves can fail to acknowledge and appropriately identify their caring role, especially if they don't co-habit, so a pro-active approach is vital.
- The carer may be identified by the service user as a part of the problem, and be unwilling to share information or involve the carer in planning.
- Many carers of those with mental illness develop depression, anxiety and other mental illnesses themselves. They may feel particularly vulnerable and at risk physically or emotionally.
- When a person has little insight into their own illness, or refuses to engage with services, the carer can be left with all the responsibility for care provision.
- If the carer is involved in invoking the mental health act, the relationship with the cared-for person can suffer as a consequence
- Dual diagnosis is the term used to describe patients with both severe mental illness (mainly psychotic disorders) and problematic drug and/or alcohol use. Drugs can make the symptoms of mental illness worse: people with dual diagnosis have complex needs relating to health, social, economic and emotional stressors or circumstances which can often be exacerbated by their substance misuse. Efforts to provide support for individuals with a dual diagnosis presents a major challenge – not least to those who care for them.

Carers of people with dementia

Carers insight and knowledge is invaluable to seeing the individual with dementia, they play a significant role in supporting the person to live well with their condition. However caring for someone with dementia can take its toll. Carers often have to deal with distressing behaviours, such as repetition, aggressive tendencies, wandering and night waking. These behaviours can be hard to know how to manage, stressful and tiring. Carers often become isolated as they are unable to safely leave the cared for person for any period of time, or the person's behaviour makes social interactions difficult. Carers may also experience a range of emotions such as loss, guilt and anger as the condition progresses. Carers need to be supported to understand dementia and how they can manage behaviours. They need

knowledge of and access to support services which can help them in their role, give them breaks, and help them feel less isolated. Carers also need to be supported emotionally and enabled to look after their own health and wellbeing.

2. Implementing the Care Act and Children & Families Act

The two pieces of legislation that will have the greatest influence on support for adult carers, young carers, young adult carers and parent carers; as well as the transition as young people prepare for adulthood are:

- The Children and Families Act 2014, which focuses on Special Educational Needs and Disability and was implemented from September 2014. Part 3 of the Act sets out the rights of young carers and parent carers
- The Care Act, which focuses on the care and support of adults with care and support needs and was implemented from April 2015. Part 1 of the Act sets out the rights of adult carers and young carers coming up to adulthood (also known as 'in transition')

Elements of both Acts are based partly on work led in Bristol. Significantly, the Children and Families Act 2014 introduces a system of support which extends from birth to 25, and some elements of good practice in Bristol influenced its development, while the Care Act deals with adult social care for anyone over the age of 18. This means there will be a group of young people aged 18-25 who will be entitled to support through both pieces of legislation, these young adults are often referred to as 'in transition'. The two Acts do have the same emphasis on outcomes, personalisation, and the integration of services, and foster a **whole family approach**.

It is essential that the planning and implementation of both of these Acts is joined up at a local level and these new laws could make a big difference to carers in Bristol, if they are implemented well. Therefore a key priority will be to focus on implementing these Acts for carers. A big challenge for Bristol City Council, the NHS and local organisations will be to implement these changes without extra resource.

The following sections look at the impact of the Acts on carers and provide a brief overview of the approach to implement the duties to ensure we are optimising the opportunities for the effective use of resources to benefit carers in Bristol.

Impact of the Children and Families Act

The Children and Families Act defines and gives rights to young carers and parent carers in law.

A young carer is identified in the Act as 'a person under 18 who provides or intends to provide care for another person but is not paid to provide the care or a formal volunteer'. A parent carer is defined as 'a person aged 18 or over who provides or intends to provide care for a disabled child for whom the person has parental responsibility'.

The Act places a duty on the Council to assess a parent carer or a young carer if it appears they may have needs for support, or if they request an assessment, or where the local authority are satisfied that they may provide or arrange for the provision of services under section 17 of the Children Act 1989:

- to safeguard and promote the welfare of children within their area who are in need; and
- so far as is reasonably consistent with that duty, to promote the upbringing of such children by their families, by providing a range and level of services appropriate to those children's needs

The assessment must cover the following:

- participation or wish to participate in education
- training or recreation
- the extent to which a young carer works or wishes to work
- whether it's appropriate for the young carer to provide, or continue to provide, care for the person in question in light of the young carers needs for support or wishes

The Act transforms the system for disabled children and young people and those with Special Educational Needs (SEN), so that services consistently support the best outcomes for them. The reforms create a system from birth to 25 through the development of coordinated assessment and single Education, Health And Care Plans; improving cooperation between all services responsible for providing education, health or social care; and giving parents and young people greater choice and control over their support.

In Bristol we are developing Education, Health and Care Plans to bring everything into one place; co-producing a series of workshops with parent carers to develop the practical process and the Bristol approach. This will deliver the 'promise' to carers set out in the reforms, to bring together formal education, health care plan, informal support plans and social care and health assessments into one place.

In addition we are developing the approach to personal budgets for children and families, which will put children and families at the core of the support.

Impact of the Care Act 2014

For the first time, adult carers will be recognised in the law in the same way as those they care for. Bristol City Council has a duty to assess all carers, if there is an appearance of need, irrespective of their level of need or their finances. All carers in Bristol will be entitled to support if:

- they are assessed as having needs that meet the national eligibility criteria
- the person they care for lives in the local authority area (which usually means their established home is in that local authority area but would also include someone who has no settled home but is present in that area)

Carers who may have needs for support, whether currently or in the future, will receive an appropriate and proportionate assessment i.e. one that is flexible and adaptable so it best fits with their needs.

Bristol City Council has undertaken a programme of work to ensure that the approaches across all care and support services (for people who use services, for people who pay for their own services ['self-funders'], as well as carers) are 'Care Act compliant'. In addition, the Council is undertaking a review of the care and support 'Customer Pathway' (how people access the right services, at the right time, to ensure their needs are met appropriately) to embed the principles of the Act through applying nationally recognised good practice, which will help the organisation to cope with the anticipated additional demand as a result of the new duties.

This alongside the training and development initiatives Bristol City Council is undertaking with its workforce and key partners will ensure the approach will move away from 'assessing for services' to one in which the assessment (including carers assessments) will identify:

- care and support needs
- what outcomes the individual is looking to achieve to maintain or improve their wellbeing
- how care and support might help in achieving those outcomes

A priority for the first year of the term of this strategy will be to map what is currently available to carers from the local authority and partner organisations, and identify the gaps or areas that need changing. This work will inform the action plan and the implementation of the necessary changes.

The overall approach being taken by the Council is to use the principles of the Care Act for wellbeing, prevention, and information and advice to look after Bristol carers so that they can carry on in their carer role for as long as possible. The Council has given an undertaking to the Carer Forums to engage and involve carers as they embed these principles to ensure expectations are aligned with the priorities identified by Bristol carers.

3. Four interventions to focus on

The interventions below have been identified as priorities by Bristol carers; and will be the focus for the term of this strategy (2015-2020) and the action plan, which will support this document.

- **Personalised breaks from caring**
- **Support for carers at times of change, including preparation for adulthood and end of life**
- **Appropriate support in an emergency**
- **Information and advice, including on benefits and financial issues**

This does not mean that the other aims, services or activities do not need any focus; we would expect work in the other areas identified above to still continue.

How we identified the priorities

This strategy has been refreshed to be in line with the new legislation as a result of the Care Act and of the Children and Families Act. The priorities and outcomes have been identified during many months of work involving carers. Some of the early work and good practice undertaken in Bristol, around access to assessments for carers, went on to inform the content of the Care Act.

During 2014, detailed consultation took place with the following, and is captured in the 'sunflower' diagram (see page 4):

- Bristol Carers Voice
- The Carers Strategy Implementation Group (CSIG)
- Bristol Parent Carers Network
- Young carers (through Young Carers Voice, and also the output of a residential weekend)
- An open meeting for carers was also held to allow anyone who wasn't associated with a particular group to input.

Personalised breaks from caring

Having a break from caring is an essential part of making the caring relationship enjoyable, sustainable and ensuring the carer has an opportunity to have a life of their own. The carer is always best placed to say what type of break would be best for them; for example, one carer might need a week away each year whilst another might need time each week to go to a class or access to a computer to stay in touch with other family members, young carers often want to have the opportunity to get support from their peers. Often a carer is unable to take a break as they are unable to leave the cared-for person, or they may feel a sense of guilt. Carers therefore need support to take breaks.

Support for carers at times of change, including preparation for adulthood and end of life

Many carers have told us that there is little information and support available at times of change; the move from childhood to adulthood, coming into and out of a caring role, times of diagnosis and discovery, crisis and recovery, loss, grief and new opportunities.

Appropriate support in an emergency

Emergency support enables carers to plan for an emergency and provides cover if the carer, for reasons of an emergency or personal crisis, is unable for a short period to continue to provide care. It cannot be assumed that carers have family or friends around them who would step in during an emergency.

Particular attention should be paid to the targeted groups of carers listed above. For example, carers from black and minority ethnic communities might require culturally sensitive cover for the cared-for person.

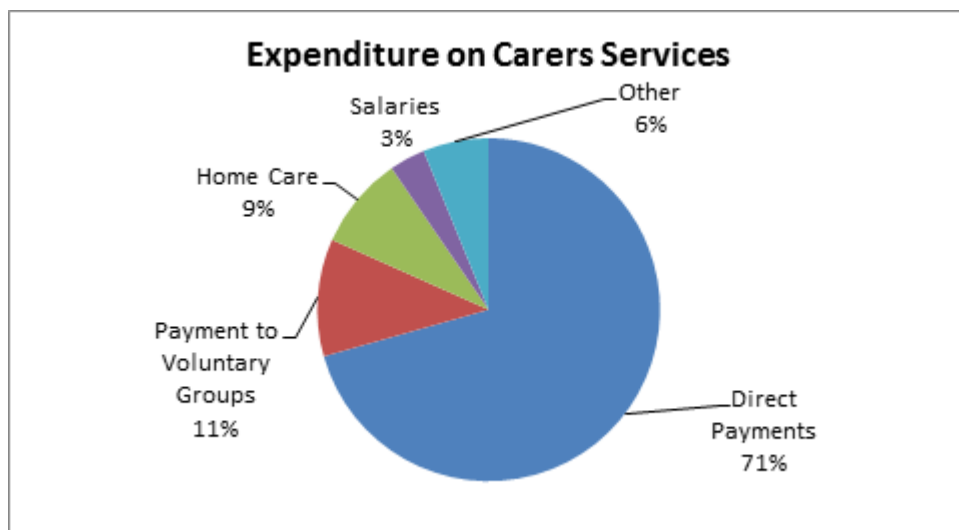
Information and advice, including on benefits and financial issues

Carers need easily accessible and often specialist information. The information a carer needs will change over time and therefore this aim has links with many of the other aims e.g. supporting carers at times of change could be about the provision of information. Up to date information is essential in light of the changes to benefits and how care and support is being delivered.

Financial analysis

Bristol CCG and Bristol City Council contribute towards a pooled budget, called the 'Better Care Bristol' Programme' (previously referred to as the 'Better Care Fund') in order to jointly provide support for carers. These budgets will continue to be pooled each year, subject to reviews by both parties, and any changes in Government legislation, and the amounts will be agreed on an annual basis.

To give an idea of how this is spent, this pie chart below shows how this pooled budget was spent during 2014/15



In 2015/16 financial year, Bristol CCG are contributing £1.036m, and £777k is coming from Bristol City Council, making a total of £1.813m for 2015/16.

The budget is administered by the Integrated Carers Team ('integrated' reflects that the team is for both children *and* adults, and that BCC and NHS have come together). Bristol City Council and the CCG meet monthly to share and monitor budget information.

In addition a number of voluntary sector organisations in Bristol receive funding from various charitable trusts to undertake additional work with carers.

Implementing the strategy

This strategy has been co-produced with Carers, Bristol City Council, Bristol Clinical Commissioning Group and partner organisations that provide support to carers; they are all members of **Bristol Carers Voice**, a Partnership Board that oversees carers' issues in Bristol.

The strategy is overseen by the **Carers Strategy Implementation Group (CSIG)** and will be implemented by a wide range of partners including Bristol City Council, Bristol Clinical Commissioning Group and other organisations.

The first step of implementing the strategy will be to develop an **action plan** to accompany this document. Carers and partner organisations will contribute to this as they know what is available now and can help to identify the gaps. Once the actions have been agreed and assigned to leads, the Carers Strategy Implementation Group will meet regularly to ensure progress and discuss any issues arising.

Other key groups involving/representing carers in Bristol

In addition '**Young Carers Voice**' group which meets monthly and looks in detail at issues for young carers. (This group is currently commissioned to the Carers Support Centre and Bristol Black Carers.). Young Carers Voice links with local and national decision-making linked to young carers, as well as raising awareness of young carers in Bristol: in schools and amongst health and social care professionals. Young Carers Voice links with the Bristol City Youth Council as an equalities forum

The Parent Carers Network

Bristol Parent Carers is a Parent Carer Organisation run by parents, with help from two support agencies (The Carers' Support Centre, and Supportive Parents). It provides a voice for families of children and young people with disabilities and special needs so they can shape the services provided by local authorities. Its aim is to become the contact point for any organisation wishing to obtain the opinions of parent carers in Bristol.

UHB & NBT Carers Reference Group: represents carers across both trusts whilst reporting specific issues to the relevant trust.

Annex A – National context

According to the 2011 Census⁵, there were approximately 5.8 million people providing unpaid care in England and Wales in 2011, representing just over one tenth of the population. The absolute number of unpaid carers has grown by 600,000 since 2001; the largest growth was in the highest unpaid care category, fifty or more hours per week.

The Census also found that there were over 166,000 young carers aged 5-17 in England – an increase of over 26,000 since 2001. The majority were providing 1 to 19 hours care but over 8% were providing 50 or more hours of care per week.

Significantly, more women than men in the age group 50-64 years were providing care. But there has been a shift in the age group of 65 and above – more men were providing care than women in 2011.

While 55% of female adult carers and 45% of male adult carers reported they were economically active, only 12% of women and 9% of men were working full-time alongside caring responsibilities and only 1% of men and women reported they were in full-time employment while providing 50 hours or more care a week.

Unpaid care has increased at a faster pace than population growth between 2001 and 2011 in England and Wales; the same is true in Wales and across all English regions other than London, where it decreased.

The Personal Social Services Survey of Adult Carers in England 2012-13⁶ showed that the highest level of carers' needs were reported among carers with mental health problems of their own, among carers from Asian/British Asian Communities, carers under age 64 years and among those who had been caring for 15-20 years. The vast majority of carers in this country are not in touch with social care.

⁵ <http://www.ons.gov.uk/ons/rel/census/2011-census-analysis/provision-of-unpaid-care-in-england-and-wales--2011/art-provision-of-unpaid-care.html#tab-National-comparisons>

⁶ <http://www.hscic.gov.uk/catalogue/PUB12630>

Annex B - Summary of relevant national legal and policy documents

Care Act 2014. This is arguably the most important piece of law setting out how carers should be supported. The Act came in to effect on 1st April 2015 and means that for the first time, carers are being recognised in the law in the same way as those they care for. Local authorities have responsibilities to provide carers with information and advice; to provide carers with preventative services; to assess a carer's need for support and provide them with that support if they are eligible.

Children & Families Act 2014. This piece of legislation gives the same rights for an assessment and support to parent carers and young carers (under 18 years) as adult carers are given under the Care Act 2014.

National Carers Strategies. *Carers at the heart of 21st-century families and communities (2008)* set out a strategic vision and outcomes for carers (see below). *Recognised, valued and supported: Next steps for the Carers Strategy (2010)* identified four priority areas for carers (see Annex A). Since that document was published, more data have become available about the extent and nature of caring responsibilities and the impact of caring on the lives of those who provide care. This has helped to shape the most recent Government policy *Carers Strategy: Second National Action Plan 2014-2016*.

The Second National Action Plan 2014-2016 sets out the following priority areas:

- Identification and recognition
- Realising and releasing potential
- A life alongside caring
- Supporting carers to stay healthy

Better Care Fund Programme. The Government announced £3.8 billion worth of pooled budgets between health and social care, starting from April 2015. This is not 'new' money but will provide financial support for councils and NHS organisations to jointly plan and deliver local services. The Care Act 2014 places a requirement on Local Authorities to work with the NHS to promote the wellbeing of carers and improve the quality of their care and support. This fund may be used to support this work. Locally this is known as *Better Care Bristol*.

Other significant sources of information in the last few years about the experiences of families and carers include the review of **Winterbourne View** and subsequent improvement plans and the reports of the **Mid Staffordshire Inquiry**. Both highlighted the importance of clear and honest communications with families and the involvement of family carers in order to maintain and improve the quality of care and support to vulnerable people.

***Carers at the heart of 21st-century families and communities (2008)* set out the following strategic vision and outcomes for carers:**

Vision: 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, while enabling the person they support to be a full and equal citizen.

Outcomes:

- Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role
- Carers will be able to have a life of their own alongside their caring role
- Carers will be supported so that they are not forced into financial hardship by their caring role
- Carers will be supported to stay mentally and physically well and treated with dignity
- Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive and to enjoy positive childhoods.

Recognised, valued and supported: Next steps for the Bristol Carers Strategy (2010)

identified four priority areas as follows:

- Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages
- Enabling those with caring responsibilities to fulfil their educational and employment potential
- Personalised support both for carers and those they support, enabling them to have a family and community life
- Supporting carers to remain mentally and physically well

Annex C – Aims and priorities of the Carers Strategy

Aims	Example of activity or service to achieve action	Which outcome(s) does it help to achieve	Outcomes and priorities (National Carers Strategy, Department of Health)
Activities for carers	Young carers summer scheme	2, 4, 5	<p>Every carer should be:</p> <ol style="list-style-type: none"> 1. Recognised and supported 2. Enjoying a life outside caring 3. Not financially disadvantaged 4. Mentally and physically as well as they can be 5. (if a young carer) thriving and protected from inappropriate caring roles 6. Treated with dignity <p>The aims in bold are priorities identified in this strategy as areas that need a particular focus.</p>
Advocacy for carers	Independent advice for carers	1, 2, 3, 4	
Personalised breaks from caring	Sitting service for cared for person	1, 2, 4, 5	
Supporting young carers to have a social life	Groups and activities for young carers	5	
Brokerage and support planning	Advice and support on personal budgets and employing care staff	1, 2, 3	
Carers shape policy and services	Training and support for carer representatives	1, 4, 6	
Support and training for carers to help them in their role	Ensuring carers have the right equipment and training to use it	1, 4, 5	
Support for carers at times of change, including preparation for adulthood and end of life	Supporting carers of people at end of life, through bereavement and people new to/in early stages of caring. Developing the 0-25 service with carers	1, 3, 4, 5, 6	
Supporting carers to get the best out of education and training opportunities	Free education and training opportunities for adult carers	2, 5	
Making sure appropriate support is available in an emergency	Emergency card and backup services available for all carers	1, 2, 4, 5	
Emotional support and counselling for carers	Carersline or other advice and help lines for carers	1, 2, 4, 5, 6	

Recognition and support for carers in the NHS	Support for carers before and after hospital discharge of the person they care for	1, 2, 3, 4, 6
Housing support, including adaptations and equipment	Carer support workers based within housing associations. Provide information on aids, adaptations and 'move on' options where appropriate	1, 3, 4
Information and advice, including on benefits and financial issues	Targeted information for carers at different stages of their caring role	1, 2, 3, 4, 5
Peer and community support	Carers coffee mornings	1, 2, 4, 5
Whole family support	Carer assessments are made following the whole family approach	2, 4, 5
Supporting carers to work and access training	IT training and employment support with links to Jobcentre plus	2, 3

Version 14.0

Annex D – Celebrating achievements; we made it happen for carers 2014

Please find the document at the following weblink

<http://www.bristol.gov.uk/improvementsforcarers>

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