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## Young Carer, Parent and Adult Carer Strategy (2016-2020)

**YOU are likely to be a carer at some point in your life. This could be at any age whether as a child, teenager or in your 20s and 30s or later in life.**

The word **carer** throughout this Strategy means someone who looks after a person; a family member or friend because that person would not be able to be safe and well without that help. It might mean young carer, sibling carer, parent carer or adult carer.

This strategy is for Young and Adult carers including parent carers and will outline the vision and commitment for ALL unpaid carers in the city.

### Who is a carer?

*A carer is someone of any age who provides unpaid support to family or friends to enable them to cope and carry on with their day to day life as they could not manage without this help. This could be caring for a relative, partner or friend who is ill, frail, disabled or suffers with mental ill-health or substance misuse*

*This is not the same as someone who provides care professionally, or through a voluntary organisation.*

*Anyone can become a carer; carers come **from all walks of life, all cultures and can be of any age**. Many feel they are doing what anyone else would in the same situation; looking after their mother, son, or best friend and just getting on with it.*

*Carers don't choose to become carers: **it just happens** and they have to get on with it; if they did not do it, who would and what would happen to the person they care for?'*

The mental and physical demands of caring can take their toll and have significant impact.

Carers are more likely to...

- struggle to continue to study or work,
- be twice as likely to be unwell as the rest of the population
- suffer financial hardship
- be lonely and unable to have a social life

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### Introduction

1 in 10 people in Sheffield are carers; they are a hidden army that is a huge strength for the city. You could be caring for your parents, children, husband, wife, partner, wider family members or friends. The person you care for may not have a visible illness or disability but the support the carer gives is vital.

Crucial for the successful delivery of this strategy, is a mind-set change by everyone so that there is a better understanding of what caring means and the impact that it has on the carer's life.

Also that:

- All services, whether they are for carers or the person they care for, are designed with and by **carers**
- Carers are **respected** as partners in the delivery of support, care and recovery
- Carers' **needs** are as important as the people they care for

This is a City Wide joint multi-agency strategy that has been developed by carers, carer advocacy groups, providers and community organisations, Sheffield City Council and NHS partners. The crucial social and economic role of carers demands that they are strategically supported across the city by all organisations.

This is a five year strategy that will set out six Carer Principles which will define the key actions and services that are required to improve carers' lives.

All partners will sign up to the six Carer PRINCIPLES and the resulting action plans to improve the lives of carers.

Providing care for someone in your family or a friend at some point in our lives is becoming increasingly common.

Many carers do not see themselves as a carer; they see it as a normal part of life or their duty.

Joint multi agency strategy

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### Our vision and SIX PRINCIPLES

Carers are really important to families and friends. Providing care is an integral part of life and many people have told us through consultation they want to care but it is not always easy.

In this Strategy we are setting out an ambitious plan for every carer to have

- a life of their own
- the choice to care and stop caring without recrimination
- equality of opportunity to life chances including education, training, work and leisure activities

Our Carers Strategy will enable families to stay well and tackle financial hardship.

And by 2020 every carer should have appropriate opportunities to:

1. Access at the right time, the right type of information and advice for them, their family and the person they care for
2. Understand their rights and have access to an assessment
3. Have a voice for themselves and the person they care for
4. Have regular and sufficient breaks
5. Continue to learn and develop, train or work (if they wish to)
6. Look after their own health

### What would a better world look like for carers?

Carers have repeatedly told us throughout the consultation:

*'If you got the services and support right for my family member, I wouldn't have any needs'*

Whilst this may be true for some, all carers' needs won't entirely disappear if support and services are right for the person they care for. So it's important that we build on carers' strengths (or assets) to reduce and address any ongoing needs.

For Young Carers, we need to ensure that professionals recognise their caring contributions and include them in

#### Our vision for Sheffield is:

*A City where Carers are **valued** and have the **right support** to continue to care for as long as they want to*

*All I want is the best possible care for the person I care for*

Many carers don't recognise their own needs.

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discussions and decisions about the people they care for.

We should not discourage caring, but it should not be a barrier. Support to care and where appropriate, alternative services should be put in place to help young carers.

Young Carers should be supported to continue care for as long as they wish to and it not be a detriment or reduce their life chances.

*We have consulted with carers, staff and providers to understand what 'good' could look like – please see [appendix 2](#)*

### Caring Costs

Caring can have a significant impact on economic wellbeing and can cause financial hardship due to:

- Difficulty attending school, completing homework or being tired and not being able to concentrate
- Leaving school / education early and not progressing to further and / or higher education
- Reduced working hours or taking periods of unpaid leave
- Having to leave work or retire early

Caring can also incur greater costs e.g.

- Travelling regularly to care for someone where they don't live in the same house
- Having the heating on all day due to someone being elderly or unwell or disabled
- Aids and adaptations and their maintenance and repair
- Specialist childcare for a disabled child

This strategy acknowledges the financial hardship of caring and will look for solutions to reduce and mitigate the impact.

*Caring costs and can have financial implications for families*

### The value of caring to Sheffield

Although caring for someone cannot be measured, research in 2015 by Carers UK and the University of Sheffield have estimated the value of the caring undertaken by carers in Sheffield to be £1,186 million (this is the estimated value cost

The value of Sheffield's unpaid caring is £1,186 million

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of providing homecare for the number of hours unpaid carers provide).

*Valuing Carers 2015 – the rising value of carers' support*

<http://www.carersuk.org/for-professionals/policy/policy-library/valuing-carers-2015>

### Why a new Strategy?

We know that in a world where there will be fewer services and more of us living longer but not necessarily in good health, the role of carers' will become more vital.

This new strategy recognises that:

- The number of carers is increasing
- Carers are getting older (21% increase of carers aged 65+ from the 2001 to 2011 census)
- Carers are providing more hours of care (18% increase at 20+ hours and 13% increase at 50+ hours)
- For some people caring is lifelong
- For other people they may care for a few years and then stop and this could happen several times
- Every day there are people starting to care for the first time (approx. 55 people in Sheffield every day)
- There are a number of factors that when added together cause health inequalities for carers e.g. emotional stress, poor health, financial hardship

We know that If we do not continue to champion carers' and enable them to continue to care it can have far reaching consequences for the carer and for the person being cared for. For example; poor mental and physical health, financially and / or socially excluded, being subject to or perpetrating abuse.

Through this strategy we will continue to build the strength and resilience of carers to continue to care for as long as they wish to.

### Local requirements

Since the last Strategy (2010-2013) there has been progress and good work but many of the concerns described in the previous and national strategies still exist in Sheffield today.

Achievements since the last Strategy:

- The Carers and Young Carers Board
- Introduction of the multi agency approach to supporting young carers
- One stop Carer Support Helpline
- Carer contingency plans
- Employment support for working carers
- Setting up of Special Educational Needs Local Offer
- Improved post-diagnosis support through specialist nurses
- Health Care planning documentation requires identification of caring responsibilities

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### National drivers

Since 2008 there have been seven national strategy documents published by Department of Health, NHS England and Think Local Act Personal. These documents are also supported by the State of Caring published annually by Carers UK.

We will publish this Strategy in 2016 and review it in light of the new national strategy which is due at the end of 2016.

See [appendix 5](#) for the list of documents and priorities

### Care Act – adult carers

The Care Act came into force in April 2015 and has introduced new responsibilities for Councils to support adults with social care needs and carers.

This replaces the previous law, which said that the carer must be providing “a substantial amount of care on a regular basis” in order to qualify for an assessment.

This new law applies to all adult carers who care for adults irrespective of whether the cared for person receives direct support from Social Services

The new assessment will consider the impact of caring on the carer where there is an apparent need for support either now or in the future. It will also consider the things that a carer wants to achieve in their own day-to-day life. It must also consider other important issues, such as whether the carer is able or willing to carry on caring, whether they work or want to work, and whether they want to study or do more socially.

**Transition:** The local authority must carry out an adult care transition assessment where there is significant benefit to a young person or their carer in doing so and they are likely to have needs for care or support after turning 18.

Young carers have a right to a transition assessment also.

If both the carer and the person they care for agree, a combined assessment of both their needs can be undertaken.

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**Children and Families Act – parent and young carers**

**Young carers:** for the first time, young carers now have rights as part of this new Act. Councils must take reasonable steps to identify young carers in their area who have support needs.

Young carers have the right to an assessment regardless of who they care for, what type of care they provide or how often. The assessment must be carried out in a way that is appropriate for the young carer's age, level of understanding and their family circumstances.

**Parent carers:** parents of a disabled child aged under 18, will be assessed as part of the assessment of their child. Alternatively parent carers have the right to a stand alone assessment and it is not dependent on the child receiving services. This will be a look at the whole needs of the family. The assessment will take into account detailed information about the family, including:

- the family's background and culture
- the family's views and preferences
- the needs of any other children in the family
- the wellbeing of the parent carer
- whether it is appropriate for the parent to provide, or continue to provide, care for the disabled child, in light of the parent's needs for support, other needs and wishes

A care plan will be drawn up that would include services to benefit both the parents and the disabled child.

The Council now has a responsibility to assess a family and young carer's needs for support.

A Young Carers Assessment process has been implemented city wide which can be completed by the Council, schools, health or care providers

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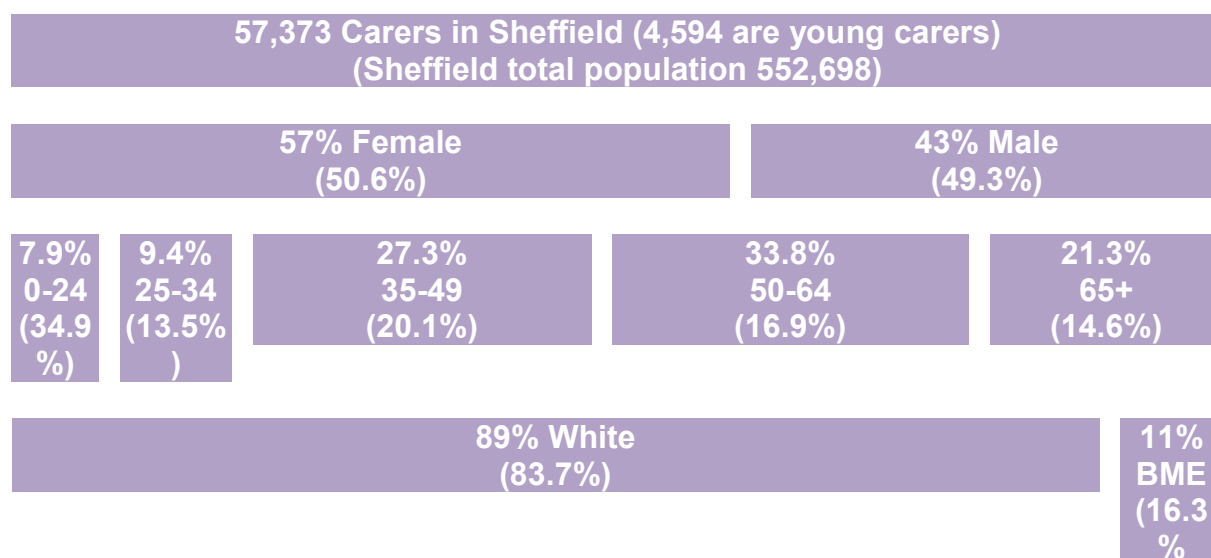
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### What is the picture in Sheffield?

The city is not unique in that our carer statistics reflect the national picture

The total population of Sheffield figures are included in brackets

1 in 10 people in Sheffield are providing unpaid care at any one time



2011 Census, NOMIS

These figures are the best estimates for carers in Sheffield. Carer is not a readily used word by families, friends or professionals for people who provide unpaid care.

Many people do not see the benefit of saying they are a carer or even identify themselves with the word, the figure in the 2011 census is probably lower than the true number of carers in Sheffield.

### More details about Sheffield's Carers:

**Young carers:** BBC research in 2012 estimated that 1 in 12 young people are young carers. This would equate to 6,000 in Sheffield. This is reflected in work undertaken locally in a number of secondary schools

**Parent carers:** national organisation Contact a Family has estimated that approximately 1 in 20 children are disabled. This would equate to approx. 27,360 children in Sheffield.

There are about 2,000 children with a Special Educational Needs Statement or Education Health and Care Plan and about 1,600 who receive a social care package.



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**BME families:** there are 7,102 BME carers in Sheffield, which is 6.7% of the BME population. Pakistani carers make up a third of the BME carer population which reflects that the Pakistani population are the largest of Sheffield's BME population (24% of the BME population).

### Carers Health Needs Assessment

The Health Needs Analysis report of carers published in 2012 used the 2001 census information. We have analysed the 2011 census data and the findings of the report broadly remain.

In comparing the last two censuses (2001 and 2011) there have been a number of changes in specific groups of carers:

- Young carers have increased significantly (15.1% increase) by 585
- An increase in the number of male carers who provide 20+ hours of care; this is most marked in the 20-49 hours bracket (+596 carers or +2.3% of all male carers)
- There is also a decrease in the number of men who provide 1-19 hours of care (844 less carers or a 4.4% reduction of all male carers).
- There has been an increase in the number of women who provide 20+ hours of care; this is most marked in the 50 hours or more group
- An increase in claiming Carers Allowance from 1.1% to 1.3%. In 2015 this rate is now 1.8% which is 0.3% above the national average but lower than the rest of South Yorkshire.
- 70% of carers reported they were in good health and 30% reported they were in fair or bad health
- 52% of carers are in employment

#### HNA Findings:

- Understanding by professionals of carers and young carers issues are still poor
- Improve identification of carers
- Carers should be offered an annual health check

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### The changing carer population

Research in 2015 by Carers UK and the University of York found that the caring population changes regularly – it is NOT STATIC.

Nationally about 2.1 million people start caring and just less than 2.1 million cease caring every year.

In Sheffield this equates to about:

- 20,000 people becoming a carer every year and
- 19,000 people stopping caring every year.

*Transitions in and out of caring: the information challenge,*  
Carers UK, Nov 2014

<http://www.carersuk.org/for-professionals/policy/policy-library/need-to-know>

**... 55 people  
start to care in  
Sheffield every  
day**

### How has the strategy been developed?

This strategy has been developed as a result of many different conversations, questionnaires, discussions and consultations with carers.

And it has also been informed by existing local reports including:

- The State of Sheffield: Parent Carer Forum Report 2014
- Young Carers Manifesto and further young carer workshops (2014 and 2015)
- Adult carers: Previous strategy, consultation via support groups, questionnaires, personal conversations and the previous consultation

Carers have set out a list of priorities which they feel are important to them. These have been used to develop the PRINCIPLES and will be central to the action plans to deliver this strategy.

*The Young Carer and Carer priorities are listed in [appendix 4](#)*

We have spent 6 months listening to carers

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### **Next Steps - HOW WILL THE STRATEGY BE DELIVERED?**

We will turn the Strategy into a reality through the development of three action plans:

1. Young Carers
2. Adult and parent carers
3. Transitions

Delivery of the Strategy will not only require direct action but also:

- The influencing of different council and CCG and NHS strategies and services, including Care Planning and Active Support and Recovery
- Investment in time, resource and training of staff to understand the needs and requirements of carers.

High level actions have been identified via the consultation and are listed below. This list is not exhaustive and will develop as work and further consultation continues:

Please note, solutions identified below may already be implemented via other strategies and change programmes

#### **Action Plans:**

- 1. Young Carers**
- 2. Adult and parent carers**
- 3. Transitions**

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Principle	Challenge	Solution	Lead organisations
<b>1. Access at the right time and the right type of information and advice for them, their family and the person they care for</b>  <b>2. Understand their rights and have access to an assessment</b>  <b>3. Have a voice for themselves and the person they care for</b>	<ul style="list-style-type: none"> <li><b>How do I access and get quality information, advice and guidance?</b></li> </ul> <p>There is a large amount of information available locally and nationally in various formats / media – the challenge is:</p> <ul style="list-style-type: none"> <li>Carers do not know how to access or find the information (you don't know what you don't know)</li> <li>Information overload</li> <li>Information too little too late</li> <li>Little information and advice to navigate the information</li> <li>Carers don't understand their rights or options available</li> <li>No enough help with Direct Payments, recruitment/employment of PAs</li> </ul>	<ul style="list-style-type: none"> <li>Information and advice available and accessible in different formats e.g. paper based, digital</li> <li>Support for carers to navigate information</li> <li>Advice and guidance to support choices and maximise income (e.g. benefits and discounts)</li> <li>Advocacy</li> <li>Primary care is a common place for carers to present, often with low level mental health issues or psychosomatic problems as well as real health issues- working with Primary care to improve their knowledge regarding signposting</li> </ul>	<b>Sheffield City Council</b>  Including: <ul style="list-style-type: none"> <li>Clinical Commissioning Group / NHS providers</li> <li>Young Carer / Carer Support Services</li> <li>Care providers</li> </ul>
	<ul style="list-style-type: none"> <li><b>A. I find Health, Social Care and Education processes difficult to understand</b></li> </ul> <p>Complicated processes and procedures that are difficult for carers to understand,</p>	<p>Easy to use <b>health, social care and education services</b>, which could include:</p> <ul style="list-style-type: none"> <li>A named contact and consistency of contact for families with higher levels of</li> </ul>	<ul style="list-style-type: none"> <li><b>Sheffield City Council</b></li> <li><b>Clinical Commissioning Group</b></li> </ul>

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Principle	Challenge	Solution	Lead organisations
	navigate and do not always deliver a fit for purpose service: <ul style="list-style-type: none"> <li>• Social care</li> <li>• Hospitals</li> <li>• Primary care</li> <li>• Homecare providers</li> <li>• Education institutions</li> </ul>	need <ul style="list-style-type: none"> <li>• Information sharing between professionals, services and providers to avoid not having to repeatedly tell the story</li> <li>• A responsive and timely system</li> <li>• Identify the care network at the Care Planning stage</li> <li>• Carers and young carers to be involved in care planning processes</li> <li>• Better liaison between health and social care e.g. hospital discharge, Active Support and Recovery</li> <li>• Management Interoperability Gateway project</li> </ul>	Including: <ul style="list-style-type: none"> <li>• Young Carer / Carer Support Services</li> <li>• NHS providers</li> <li>• Care providers</li> </ul>
		<b>Improvements in Council commissioned Homecare providers:</b> <ul style="list-style-type: none"> <li>• Quality of staff and care given</li> <li>• Timeliness of appointments</li> <li>• Processes and timeliness between Social Care and provider</li> </ul>	<b>Sheffield City Council</b>  Including: <ul style="list-style-type: none"> <li>• Care providers</li> </ul>

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Principle	Challenge	Solution	Lead organisations
		<ul style="list-style-type: none"> <li>Transfer of information / assessments between Social Care and care providers</li> </ul>	
	<b>B. I need help to plan for emergencies and contingencies</b>	<b>Emergency planning</b> - carers want tools and support to complete and maintain an emergency plan  Linking with existing citywide care plans such as 'OK to Stay'	<ul style="list-style-type: none"> <li><b>Sheffield City Council</b></li> <li><b>Clinical Commissioning Group</b></li> </ul> Including: <ul style="list-style-type: none"> <li>NHS providers</li> <li>Young Carer / Carer Support Services</li> <li>Care providers</li> </ul>
	<b>C. Staff do not recognise me as a carer or help me</b>  Carers and young carers are not consistently identified, acknowledged, given information or included in decisions about the people they care for. Staff do not: <ul style="list-style-type: none"> <li>Identify carers and recognise their needs</li> </ul>	<b>Carer aware workforce</b> – training for all frontline staff to: <ul style="list-style-type: none"> <li>Recognise carers and the issues they face</li> <li>Support plan for the whole family including carers</li> <li>Utilise and recognise the knowledge and expertise of the carer in supporting / recovery of the cared for person</li> </ul>	<ul style="list-style-type: none"> <li><b>Sheffield City Council</b></li> <li><b>Clinical Commissioning Group</b></li> </ul> Including: <ul style="list-style-type: none"> <li>NHS providers</li> <li>Young Carer / Carer Support</li> </ul>

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Principle	Challenge	Solution	Lead organisations
	<ul style="list-style-type: none"> <li>Treat them as equal partners and recognise their importance in the support and recovery of the person they care for</li> </ul>	<ul style="list-style-type: none"> <li>Greater understanding by all agencies such as; social care, health, education and housing staff about the rights of young carers</li> </ul>	Services <ul style="list-style-type: none"> <li>Care providers</li> </ul>
	<p><b>D. Am I a carer?</b></p> <p>Hidden carers – people who do not identify or recognise themselves as carers and therefore are not known to services or know how to access support and help</p>	<p><b>Communication campaign</b> with multiple approaches including communities, primary care and hospitals to identifying carers and explaining the benefits of accessing help</p> <p>Linkages with existing change programmes such as People Keeping Well and Integrated Commissioning Programme will be key to reaching people who don't consider themselves a carer</p>	<ul style="list-style-type: none"> <li><b>Sheffield City Council</b></li> <li><b>Clinical Commissioning Group</b></li> </ul>
<b>4. Have regular and sufficient breaks</b>	<p><b>E. I cannot get a break</b></p> <p>Carers are not able to get a <b>suitable or fit for purpose break</b>:</p> <ul style="list-style-type: none"> <li>Not clear what break options are available or very limited choice</li> </ul>	<p>Develop <b>different 'break' options</b> which are responsive to and reflect carers needs</p> <p>May include; specialist building based, short breaks, care or nursing home, home based,</p>	<p><b>Sheffield City Council</b></p> <p>Including:</p> <ul style="list-style-type: none"> <li>Young Carer / Carer Support Services</li> </ul>

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Principle	Challenge	Solution	Lead organisations
	<ul style="list-style-type: none"> <li>Not being able to pre book respite</li> <li>Carers do not want a break on their own but would like to 'do something nice' with their family member</li> </ul>	<p>Sharing Lives, meaningful activities, personal budgets</p> <p>Increase awareness of what respite options are available so carers can make informed choices about taking a break.</p>	<ul style="list-style-type: none"> <li>Care providers</li> </ul>
	<p><b>F. I am lonely and isolated</b></p> <p>Carers report that they are lonely as friends and other family members do not understand / drift away as the demands of caring increase</p>	<p>Develop <b>social assets and capital</b> of carers e.g. 'knit and natter', sport activities, support groups, telephone befriending, buddies, local and national online forums / chat rooms</p> <p>Primary care is a common place for carers to present, often with low level mental health issues or psychosomatic problems as well as real health issues- working with Primary care to improve their knowledge regarding signposting</p>	<p><b>Carers Support Services</b></p> <p>Including:</p> <ul style="list-style-type: none"> <li>Local and community services</li> </ul>
<p><b>5. Continue to learn and develop, train or work (if they wish to)</b></p>	<p><b>G. I am not able to learn or train</b></p> <p>Not able to have the same opportunities to <b>learn and achieve</b>, which leads to</p>	<ul style="list-style-type: none"> <li>Training and awareness for educational staff (school, college, training providers) to understand young carers /</li> </ul>	<p><b>Schools and Colleges</b></p> <p>Including:</p>



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Principle	Challenge	Solution	Lead organisations
	<p>financial hardship</p> <p>School / college / university does not understand the care role that young carers / carers have resulting in issues such as:</p> <ul style="list-style-type: none"> <li>• Being late for school, repeatedly tired, unable to complete homework or attend out of school activities</li> <li>• Achievement</li> <li>• Barriers to progression on to further and higher education</li> <li>• Emotional toll</li> <li>• Lack of specialist childcare</li> </ul>	<p>carers needs</p> <ul style="list-style-type: none"> <li>• Policies implemented to support adult and young carers to achieve in their learning</li> </ul>	<ul style="list-style-type: none"> <li>• Sheffield City Council</li> <li>• Young Carer / Carer Support Services</li> </ul>
	<p><b>H. I am not able to continue to train or work</b></p> <p>Not having the same opportunities to <b>volunteer, train, gain or retain employment</b>, which leads to financial hardship - employers do not understand caring requirements:</p> <ul style="list-style-type: none"> <li>• Lack of understanding on legislation and policies</li> </ul>	<ul style="list-style-type: none"> <li>• Training and awareness for employers to understand young carers / carers needs and the benefits of having a diverse workforce and how flexible working can be used to retain staff.</li> <li>• Policies implemented to support adult and young carers to continue to work for as long as</li> </ul>	<p><b>Young carer / Carer support services</b></p> <p>Including:</p> <ul style="list-style-type: none"> <li>• Sheffield City Council</li> <li>• Clinical Commissioning Group</li> </ul>

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Principle	Challenge	Solution	Lead organisations
	<ul style="list-style-type: none"> <li>• Fluctuating situations</li> <li>• Impact of caring on mental health, tiredness, concentration</li> <li>• Lack of suitable childcare for disabled children</li> </ul>	they wish to	<ul style="list-style-type: none"> <li>• Employers</li> <li>• Training and apprenticeship providers</li> </ul>
<b>6. Look after their own health</b>	<p><b>I. I am not able to look after my own health</b></p> <p>Caring itself, impacts on physical, mental or emotional health - carers ignore or are unable to look after their own health requirements e.g. delay operations or miss appointments as they cannot get replacement care</p>	<ul style="list-style-type: none"> <li>• Training for health staff to recognise carers and understand the impact of caring on carers health and how to support them effectively</li> <li>• Targeted health interventions for carers e.g. flu jab, carers check ups, screening programmes</li> <li>• Flexible options for carers to access health appointments e.g. cannot attend same day appointment because cannot organise replacement care</li> <li>• Awareness raising so carers understand their own health and wellbeing is important. Empowering carers with health conditions to self-manage their condition.</li> </ul>	<p><b>Clinical Commissioning Group NHS Providers</b></p> <p>Including: Young Carer / Carer Support Services</p>

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## **Monitoring and Evaluation**

This Strategy will be published by 2016 and will be reviewed to reflect the new national strategy (due to be published end 2016)

The delivery and achievement of the action plans will be accountable to:

1. All Carers
2. Carers and Young Carers Board
3. Young Carers Strategic Board and subgroups
4. Carers Service Improvement Forum
5. Carers Hub

The action plans will not be static plans and will be reviewed yearly to monitor progress and achievement of actions and outcomes. As action plans are reviewed, further priorities may be identified and these will be included.

Key measures of success will be

- Carers telling us
- Adult Social Care Outcomes Framework

## **Commissioning Plans and Support Services**

Young and adult / parent support services for carers are not jointly commissioned and therefore a commissioning plan is not included in this strategy.

Commissioning for Young Carers Support Services was completed for January 2015 and the strategy will define future intentions.

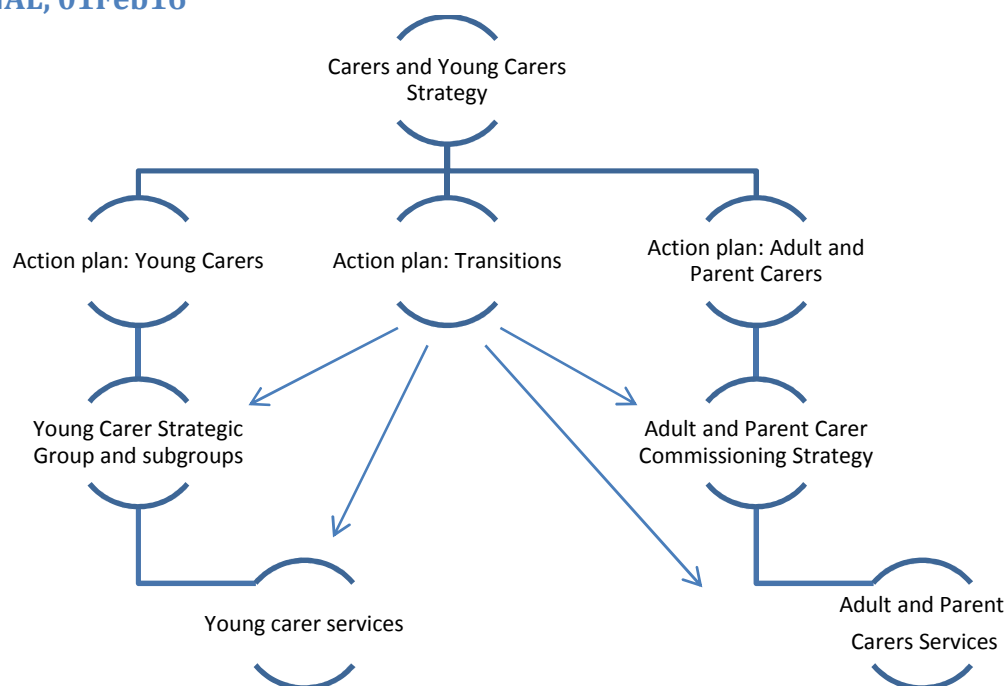
There will be an Adult and Parent Carer Commissioning Strategy published early 2016 outlining the future of support services for adult and parent carers.

The Commissioning Strategy will include how support services for carers will align with other health and social care commissioning priorities.

*See the diagram below to show the relationships*

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### Appendices

#### 1. Definitions

<b>Adult Carers</b>	are adults caring for adults over the age of 18. This includes adults caring for their adult children.
<b>Young Carers</b>	are children and young people under the age of 18 who provide regular and on- going care and emotional support to a family member who is physically or mentally ill, disabled or misuses substances. The term does not apply to the everyday and occasional help around the home that may often be expected of or given by children in families.
<b>Sibling carers</b>	Are either children or adults who care for a brother or sister
<b>Young Adult Carers</b>	are young people aged between 16 and 25 who are caring either for another child or young person, or an adult.
<b>Parent Carers</b>	are parents caring for a disabled child or young person under the age of 18. Parents will often see themselves primarily as parents however their child will have additional care needs and may be entitled to additional services.
<b>Transitions</b>	A key change in either the carer's or the cared for's life e.g. <ul style="list-style-type: none"><li>• Starting school, moving to new schools</li><li>• Moving from Childrens to Adult Services</li><li>• No longer able to care</li></ul>
<b>Strategy</b>	A plan to achieve a long term goal
<b>Commissioning strategy</b>	Planning to develop and deliver Carer Support Services
<b>Health Needs Assessment</b>	Review of the health needs of carers
<b>Advocacy</b>	Supporting, speaking and acting on behalf of the carer
<b>Contingency plan</b>	A plan for unexpected or emergency situations
<b>SEN</b>	Special Educational Needs

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### **2. What 'GOOD' could look like for Carers**

The following list what carers and organisations have suggested 'GOOD' would look like for them:

1. Good shouldn't have to be anything specific as everything should be working
  - People know they have a real choice in how / when / where they care
2. Everything is working as it should
  - Equilibrium – life is on a level / even keel – everything is ticking along
  - Be able to trust the care Mum receives
  - Carer can relax and take a break
  - Not feeling guilty
3. Carers identify themselves as a carer
4. Carers continue to care for as long as they want to with the support they need
5. The cared for person's needs are met
  - Knowing the person you care for is safe and well
  - Reliable services that can respond to someone when they need help
  - Trusted workers that are familiar and understand the family
6. Information and advice in a timely way throughout the carer lifecycle
  - Understanding and knowledge of how to navigate the system – changes that are communicated
7. Carers are listened to by professionals
  - Don't have to repeat your story
8. Carers that have a backup plan
9. Professionals have a dual approach:
  - For the person who is the patient / service user
  - For the carer
10. Carers to continue at school / college / work for as long as they want to
11. For carers to manage their own health needs
12. Having a break
  - A 'normal' life – the cared for needs are met whilst the carer can have a break / socialise / work

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### **3. Carers contribution to the economy**

#### **Royal College of GPs**

<http://www.rcgp.org.uk/clinical-and-research/clinical-resources/carers-support.aspx>

"1.2 million carers spend over 50 hours caring for others, this equates to a full time workforce larger than the entire NHS. Carers are estimated to save the UK economy £119 billion a year in care costs, more than the entire NHS budget and equivalent to £18,473 per year for every carer in the UK."

#### **NHS England**

<http://www.england.nhs.uk/commissioning/comm-carers/>

Commissioning for carers: Principles and resources to support effective commissioning for adult and young carers. The study indicates that this could equate to a saving of almost £4 for every £1 invested.

#### **Department of Health – Impact Assessment (Carers)**

<http://www.legislation.gov.uk/ukpga/2014/23/impacts>

The Impact Assessment published by the Department of Health (October 2014) makes an estimate of the "monetised health benefits" of additional support for carers. This estimates that an anticipated extra spend on carers for England of £292.8 million would save councils £429.3 million in replacement care costs and result in "monetised health benefits" of £2,308.8 million. This suggests (as a ratio) that each pound spent on supporting carers would save councils £1.47 on replacement care costs and benefit the wider health system by £7.88.

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### Valuing Carers 2015 - The rising value of carers' support

<http://www.carersuk.org/for-professionals/policy/policy-library/valuing-carers-2015>

**The economic value of the contribution made by carers in the UK is now £132 billion per year** almost double its value in 2001 (£68 billion).

**£132 billion is close to the total annual cost of health spending in the UK**, which was £134.1 billion<sup>1</sup> in the year 2014-2015.

**Carers' contribution is growing** – the 2015 figure is **7% higher** than the figure for 2011. This is mostly because carers are providing more hours of care (82%), and partly due to the increased hourly cost of paid home care (18%).

The figures mean that, in 2015, the value of the contribution made by the UK's carers saves the public purse enormous sums every week, day and hour of the year:

- £2.5 billion per week
- £362 million per day
- £15.1 million per hour

The figures below are the estimated figures for Sheffield

	Carers 2015	Change in no. of carers 2001-15	Change in no. of carers 2011-15	Value in 2001	Value in 2011	Value in 2015	Change 2001-15		Change 2011-15	
	(Number)	(%)	(%)	(£m)	(£m)	(£m)	(£m)	(%)	(£m)	(%)
Sheffield	59,870	7	4.4	679	1,116	1,186	507	74.6	70	6.2



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4.

### Sheffield Adult Carers Priorities

1. Information and advice: I want the information I need, when I need it

For example

- a. Information that is timely, easily available and relevant to my situation
- b. Information that is easy to understand e.g. Plain English
- c. Emotional support from other carers so I can talk to people who understand what it's like e.g. carers support groups
- d. Someone to give advice who knows the health/social care system
- e. A knowledgeable person who can help with form filling, paperwork and other practical support if I need it
- f. Confidentiality is not used as a barrier to communication with me as a carer

*When we got the diagnosis, we got given lots of leaflets which had lots of information that wasn't relevant to my husband and I didn't have the time to sort through it myself*

2. I want good advice to help me through the maze

For example

- a. Support through the 'maze' of health/social care and good information about processes and timescales
- b. Good communication so that information is shared and I don't have to tell my story over and over again
- c. Good and timely information about transition periods e.g. moving from Children's to Adult services, moving to a care home
- d. One point of contact for me so it's easier to access information, advice and guidance
- e. All professionals talk to me about the needs of the person/people I care for and respect my expertise and knowledge as the carer

*I called social services, they passed me on to one person and they weren't the department. This happened three or four times, they were all pleasant but it didn't sort my problem.*

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3. If services are right for the cared for person then it will make it easier for me

For example

- a. People delivering care and support who are reliable, knowledgeable and trustworthy
- b. Continuity of care so professionals get to know the person/people I care for
- c. The care worker gives care and support whilst with the person/people I care for, for the full allocated time
- d. Training for staff who work with the person/people I care for so they understand their specific conditions/disabilities
- e. Regular evaluation and monitoring of services to ensure good quality

*When we got allocated a care worker, they didn't know anything about my Mum even though we had told our story a number of times. She is alright but doesn't always turn up on time or do quite the right things.*

4. Time for me so I can have a life outside of caring

For example

- a. Time for me so I can have a life outside of caring
- b. Flexible respite that gives me a break from being a carer
- c. Time to myself so I can go to work, have interests or hobbies without worrying about the person/people I care for
- d. Time and support to manage my own health needs – with carer friendly GPs and health services
- e. Local activities for me as a carer and inclusive activities I can do with the person/people I care for e.g. peer support groups, Cafes, gym

*I had to come home early from holiday because my husband was so unhappy in respite.*

*I never get to go to the cinema anymore because I can't get respite in the evenings.*

*I don't want a break from my wife; I would like a support worker to help us go to a concert like we used to do.*

*I have had to give up work, it was too stressful, they didn't understand why I was late all*

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*the time*

*I don't get to have  
a conversation  
with anyone now  
since my husband  
has had a stroke*

5. I want to feel in control and safe and have a plan for emergencies

For example

- a. I want to feel in control and safe and have a plan for emergencies
- b. A plan so I know who to contact in an emergency.
- c. A card scheme or way of letting people know I care if anything happens to me.
- d. Having access to training such as first aid, hygiene, moving and handling, etc
- e. Staff with good listening skills who sort out issues promptly so there is no breakdown in care

*I still wake up in  
the night and  
worry what will  
happen to my son  
when I am no  
longer here*

6. I don't want to be in financial hardship

For example

- a. I don't want to be in financial hardship
- b. Easily accessible information/services so I know what benefits or support I'm entitled to e.g. Carers Allowance/personal budgets/direct payments.
- c. Support to help me through the process of appeals or tribunals in relation to benefit claims
- d. A wide range of affordable local activities for me and the person/people I care for
- e. Knowing where I can get discount due to me being a carer

*We have the  
heating on all day  
and the gas bill is  
so high*

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Sheffield Young Carers Priorities		
Priority	Young Carers Manifesto	Outcomes
a. Education, training and employment.	2. We care for free why not help us?	Young carers are supported in school, college and other educational settings, and are supported in training and employment.
b. Health & Wellbeing of young carers.	3. You built us, don't then break us. 6. Don't let us go unnoticed. 10. Mind over Matter.	Suitable information, guidance and support in place to help young carers stay physically and emotionally well.
c. A voice in care decisions.	1. Stigma Sling ya Hook 7. We all deserve a say in the services we use day to day. 9. You have a VOYCE, use it, don't lose it.	Enable young carers to be more involved in the care plans of those they care for.
d. A strategic voice.	7. We all deserve a say in the services we use day to day. 9. You have a VOYCE, use it, don't lose it.	Ensure carers have a voice in strategy, policy and commissioning.
e. Rights and Legislation	8. If rights could talk ours would be silent	Young carers have an understanding of their rights, legislation and services available to them including financial support available to their family.
f. Transition	3. You built us, don't then break us.	Young carers are supported through the multiple periods of transition they may face.
g. Respite	4. Fancy a break? Well we do too. 2. We care for free, why not help us?	Ensure young carers have respite from their caring role.

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## **5. National and Local Policy documents**

### ***National:***

- a) Carers at the heart of 21st-century families and communities (DH 2008)
- b) Recognised, valued and supported: Next steps for the Carers Strategy (DH 2010)
- c) Carers Strategy: Second National Action Plan 2014 -2016 (DH)
- d) NHS England's Commitment to Carers (NHS April 2014)
- e) Commissioning for Carers: Principles and resources to support effective commissioning for adult and young carer (NHS Dec 2014)
- f) RCGP Supporting Carers in General Practice
- g) Making it Real for Carers (TLAP May 2013)
- h) Hidden from view: The experiences of young carers in England (The Children's Society 2013)

### ***Local:***

- a) State of Sheffield: The views of parents of children and young people (aged 0-25) with disabilities and/or additional needs (November 2014)
- b) Young Carers Manifesto, We Care. Do You? (October 2014)
- c) Views of young carers explained (VOYCE) project presents: Consultation report 2012
- d) Sheffield: a city where every Carer matters; A joint strategy for transforming the lives of carers in Sheffield 2010 – 2013