

North Tyneside's Commitment to Carers'



NHS North Tyneside
Clinical Commissioning Group



North Tyneside
Carers' Centre



North Tyneside Council

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Foreword

Carers play an absolutely vital role in our communities. Without them, the healthcare system would simply not be able to function and thousands of people with care needs would be left without support. We also know that the invaluable work carers provide goes largely unnoticed.

We already have some excellent services in place to support carers, and the people who use these services tell us what a huge difference they make in their lives, but we know we need to do more to reach carers who as yet, do not have access to support.

We welcome the introduction of the new Care Act 2014 and Children and Families Act 2014 and the long-overdue statutory recognition it gives to unpaid carers. North Tyneside now needs to review its 'Carers' Offer' which is aimed at stopping needs escalating unnecessarily when caring significantly affects the life of the carer, and where caring duties threaten to overwhelm individuals' wellbeing and relationships.

North Tyneside's Commitment to Carers builds on the successes of the North Tyneside Joint Adult Carers' Strategy and incorporates the updated North Tyneside Young Carers Strategy. The document sets out how we intend to respond to the needs of all carers who regularly care for ill or disabled family members and friends. It will also take account of the views of parents/carers of disabled children to ensure there is a single strategic document outlining our priorities for supporting all unpaid carers in North Tyneside.

What is our Commitment?

To improve the health and wellbeing of all carers living in North Tyneside, and support them to have a life outside of caring.

To actively promote open, honest working in co-production with carers.

1. Background and Introduction

The 2011 Census found that 5.4 million people in England were providing unpaid care (the same proportion of the population as reported in 2001). Over a third were providing 20 or more hours care each week, an increase of 5% on 2001 figures.

There are 166,363 young carers in England, according to latest census data released on 16 May 2013 – an increase of over 26,000 since 2001. The number of five to seven year old young carers in England has also increased by around 80% in the previous 10 years to 9,371.

Our rapidly ageing population and longer life expectancies mean that the number of older people in need of care and support is expected to outstrip the number of working age family members able to provide it as early as 2017. More people who have disabilities from birth are living on into adulthood and later life. In addition, many people are surviving serious illnesses such as cancer or stroke. Consequently the number of people living with long-term conditions is increasing, creating new demands for health and social care services.

The number of people caring around-the-clock is growing rapidly; there has been a 25% increase in the number of carers providing 50 or more hours a week of unpaid care in the last 10 years.¹

The Census also indicates that the general health of carers deteriorates in line with the increasing hours of care they provide. 5.2% of carers reported that their own health was 'not good', this rose to almost 16% among those caring for more than 50 hours a week.

Since the launch of the North Tyneside Joint Adult Carers' Strategy in 2012 the Carers' Centre, Clinical Commissioning Group (CCG) and the Council have made a lot of progress with the actions that were identified, in particular we have:

- Strengthened our approach to safeguarding carers;
- Introduced a Carers Breaks and Opportunities Fund to support carers in their caring role;
- Developed additional ways for carers to access emotional support;
- produced a *North Tyneside Carers' Guide to Health and Wellbeing* to support carers to consider their own health and wellbeing;
- Developed a Carers' Charter and recruited a number of Carers' Champions;
- Worked with local employers to identify barriers to carers seeking/maintaining employment; and
- Worked with carers to change local policies and services.

The North Tyneside Young Carers Strategy & Action Plan 2010-2013 has also made a significant difference to young carers, this includes:

- Strengthening links with Public Health School Nurses to improve identification of and support for young carers;

¹ State of Caring 2015 – Carers UK

- Utilising young people's drug and alcohol services to identify young carers and refer to the Carers centre to maximise early identification and provision of support;
- Ensuring young carers have been represented on the Youth Council;
- Co-delivery of the Local Safeguarding Children's Board's Parental drug and alcohol misuse; impact on children, young people and families training;
- Establishing a mechanism for identifying 16-18 year olds with caring responsibilities who may be eligible to access an educational bursary;
- Significantly increased the availability of emotional support to young carers including the provision of family support workers and wellbeing support sessions;
- Encouraging young carers to produce their own awareness raising materials with colleagues in the YMCA; and
- Developing term time clubs and holiday clubs to enable meetings with other young carers.

The North Tyneside's Commitment to Carers has been developed in partnership between:

- Carers;
- North Tyneside Clinical Commissioning Group;
- North Tyneside Carers' Centre;
- North Tyneside Council;
- Carers Voluntary Sector Forum; and
- Healthwatch North Tyneside.

Building on previous achievements in working with carers, this Commitment aims to provide a framework for informing future joint working to achieve the best possible outcomes for carers and the people they support.

2. National Drivers

The Care Act 2014

The Care Act 2014 places additional duties and responsibilities on local authorities with regard to supporting carers. There is a greater focus on the provision of advice and information which needs to be timely and in an appropriate format. It also places greater responsibility on local authorities to assess a carers own needs for support and explore the outcomes that a carer wants to achieve in their daily life, the impact of caring responsibilities on their desire and ability to work and to partake in education, training or recreational activities.

Impact of the Care Act on Carer Support

From April 2015 the Care Act entitles carers, and the people they care for, a right to an assessment of their needs, regardless of their income and finances or their level of need. This is a change to the previous position where a carer had to show they provided 'regular and substantial' care to be entitled to a carer's assessment.

Carers may be eligible for support even if the cared for person is not eligible where they are providing 'necessary care' to that individual. Although not all carers will be eligible for care and support they may still benefit from the opportunity to talk about their situation and how they are feeling with someone who has a level of understanding of carers needs.

The Adult Social Care Carers Assessment was updated in April 2015 to incorporate the changes the Care Act introduced. The new Carers Wellbeing Assessment provides an opportunity to listen to carers, explore the impact of caring and offer a range of options for support, both practical and emotional.

During the assessment the carer is asked to think about their caring role which includes:

- How much time the caring role takes up and whether they have time to do the things that are important to them;
- Family pressures and how caring may be affecting any responsibilities they have for a child;
- How the caring role affects their lifestyle and meeting their own needs;
- Whether they care for others;
- If caring is affecting them being able to maintain their own home; and
- Any employment issues they have, or if it affects opportunities for training, education or volunteering.

Support provided can vary from emotional support to replacement care. Carers are also entitled to a Personal Budget in their own right. This is an amount of money that can contribute towards, or support the carer to have, a break from caring. This may be goods or activities to meet specified outcomes the carer has identified during the assessment.

The Children and Families Act 2014

The Act enables local authorities to combine the assessment of a young carer with an assessment of the person they care for. Following an assessment, a decision has to be made whether the young carer has needs for support and whether this should be provided under Section 17 of the Children Act 1989.

Parent /Carers of Disabled Children

The Act also simplifies the legislation relating to parent carers of disabled children, making rights and duties clearer to both parent and practitioners. It removes the requirement for such carers to be providing "a substantial amount of care on a regular basis" in order to be assessed, and it requires local authorities to assess parent carers needs for support on the appearance of need, as well as on request.

The Local Authority must consider whether the disabled child cared for and the disabled child's family are persons for whom they may provide or arrange for the provision of services under Section 17/Child in need.

New rights for carers in the Care Act 2014 and Children and Families Act 2014 should make it easier for carers to access the essential help and support they need.

Carers Strategy: Second National Action Plan 2014–2016, Department of Health

This Action Plan builds on the previous Government's National Carers Strategy of 2008 and the Coalition Government's update of 2012. It retains the strategic vision for recognising, valuing and supporting carers from 2008 and the four areas for priority action identified in 2010 by the Coalition Government.

- 1: Identification and recognition
- 2: Realising and releasing potential
- 3: A life alongside caring
- 4: Supporting carers to stay healthy

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, whilst enabling the person they support to be a full and equal citizen.

NHS England Commitment to Carers

This document sets out a series of commitments that NHS England will do to support carers, reflecting what NHS England has heard from carers during a number of engagement events.

- "Recognise me as a carer" (this may not always be as 'carers' but simply as parents, children, partners, friends and members of our local communities);
- "Information is shared with me and other professionals";
- "Signpost information for me and help link professionals together";
- "Care is flexible and is available when it suits me and the person for whom I care";
- "Recognise that I may need help both in my caring role and in maintaining my own health and well-being";
- "Respect, involve and treat me as an expert in care"; and
- "Treat me with dignity and compassion".

Better Care Fund (BCF)

The £3.8 billion Better Care Fund (BCF) was announced by the Government in the June 2013 Spending Round, to support transformation and integration of health and social care services to ensure local people receive better care. The BCF is a pooled budget that shifts resources into social care and community services for the benefit of the NHS and local government. The total amount earmarked for the Better Care Fund in 2015/16 is £5.3bn, although it should be noted that this is not all new money.

There was a requirement that plans should include the support that would be made available to carers, reflecting the inclusion in the fund of £130m for carers' breaks in 2015/16.

3. Strategic Priorities

North Tyneside Clinical Commissioning Group (CCG)

The NHS 5 year forward plan describes the role CCG's must play in developing long term commissioning plans for the local population that demonstrate how services will, in the future, focus on health and wellbeing and not just treating ill health. In North Tyneside the initial focus is on improving services for the most vulnerable, and for complex groups such as people with learning disabilities and frail older people. It is important that CCG's work with partners in health and social care to help shape what approaches are needed to achieve improved outcomes for the local population.

The vision for the North Tyneside Clinical Commissioning Group is:

"Working together to maximise the health and wellbeing of North Tyneside communities by making the best possible use of resources"

The Strategic Principles for the CCG are:

- High quality care that is safe, effective and focused on patient experience;
- Services coordinated around the needs and preferences of our patients, carers and their families;
- Transformation in the delivery of health and wellbeing services provided jointly with the local authority, other public sector organisations and the private and voluntary sector;
- Best value for taxpayers' money and using resources responsibly and fairly; and
- Right services in the right place delivering the right outcomes.

The CCG Strategic Plan outlines the challenges for North Tyneside which includes:

- Ageing population with increasing needs;
- Health inequalities between localities;
- Increasing over reliance on hospital based services;
- Increasing high cost drugs and cost of new medical technologies; and
- Minimal growth in financial allocations and funding shift to social and primary care.

Supporting people to self-care and manage their long term conditions and minor injury and illness, where this is appropriate, is central to the vision for the future health economy. The CCG will continue to support carers, who play a crucial role in supporting patient needs, and help people to make an informed choice about their treatments in consultation with their GP.

A key priority for the CCG moving forward is to better understand how it can most effectively support primary care and other partners in their work around carers. This may include:

- Improving access to education, training and information;
- Introducing person centred care (care planning and coordination);
- Working with primary care colleagues to encourage involvement of family carers in care planning discussions for those patients with on-going health needs, attending patient reviews etc.; and
- Service development.

In addition, the CCG will continue to demonstrate progress to NHS England's Commitment to Carers, this will include:

- Completion of NHS England's self- assessment tool;
- Ensuring that service specifications and contracts include measurable outcomes in relation to the provision of support for carers.
- Ensuring the CCG is better at involving patients and carers, and empowering them to manage and make decisions about their own care and treatment; and
- Raising the profile of carers in health services.

Our North Tyneside Plan

The Council plan 'Our North Tyneside' 2014-2018 included the following aims that are relevant to how carers are supported:

- Our People will be listened to by services that respond better and faster to their needs
- Our People will be supported to achieve their full potential, especially our children and young people
- Our People will be supported to live healthier and longer lives
- Our People will be cared for and kept safe if they become vulnerable
- Our Economy will have local people that have the skills which businesses need



Creating a Brighter Future

In response to financial pressures the Council has embarked on a change programme called – Creating a Brighter Future which has 3 themes:

- **Ready for School Work and Life** – giving young children the best possible start in life and supporting people to be ready for work
- **Cared for Safeguarded and Healthy** – Supporting and safeguarding those who need care and support and are living with long-term illness or disability. Keeping

people as independent as possible and preventing or delaying the need for longer-term more intensive support

- **Great Place to Live and Work** – making North Tyneside a borough that people want to live and work in

4. Local Drivers

North Tyneside Council

North Tyneside Council's approach to supporting carers aligns with the themes of **Ready for School, Work and Life** and **Cared for Safeguarded and Healthy** of the Creating a Brighter Future Programme.



The North Tyneside Commitment to Carers' is also aligned with the **Children and Young People's Plan 2014-2018** and supports all the priorities 'Safe, Supported and Cared For'. The approach will help ensure the most vulnerable children in North Tyneside are supported at the earliest opportunity, reducing the number of children and families requiring specialist support.

Safeguarding

We recognise that carers can be particularly vulnerable and safeguarding both the carer and also the person they care for is very important.

Since the last carers strategy there has been a significant amount of work carried out to look at how we can identify and support people who are particularly at risk.

All organisations involved in producing this Commitment will continue to work in partnership to ensure the needs of carers are met in a co-ordinated way and also to support carers to speak up about abuse.

Carers' Charter and Champions for Adult Carers

The North Tyneside Carers' Charter was developed by carers and sets out the key principles when working with carers, these include:

- Recognising carers
- Valuing carers
- Providing information and advice to carers
- Involving carers

The Carers' Charter was produced to promote the inclusion of carers in planning and decision-making and to support individual carers to participate as required. Work is needed to ensure that both the Council and CCG ensure the principles of the Charter are embedded across their organisations.

Service providers who are commissioned by the Council and CCG are expected to agree to the principles of the Carers' Charter. To ensure it is making a difference both organisations need to develop a robust framework within their quality monitoring processes, to measure the extent to which the Charter is being implemented across services.

To further develop the support for carers', a network of Carers' Champions was established. Champions are people with a passion for improving the experience of carers who come into contact with their service by supporting their colleagues and being knowledgeable and influencing best practice for carers. Originally 17 people signed up to be a Champion, however changes in roles and responsibility has resulted in the number of active Champion's reducing. There has also been some confusion about the role of the Carers' Champion, which needs to be addressed in any subsequent launch. North Tyneside Council has appointed a number of Carers Champion's within services. Councillor Alison Waggott-Fairley is the lead Member Champion who has corporate responsibility for ensuring carers' rights and needs are considered during council meetings and service developments.

A re-launch of the network and additional recruitment of Carers' Champions, which will potentially include Young Carer Champions', is needed to ensure the success of North Tyneside's Commitment to Carers.

[Appendix 1 - Carers' Charter](#)

Parents Carers of Disabled Children and Partnership Working

The Children and Families Act 2014 requires Local Authorities, CCG's and NHS England to develop effective ways of harnessing the views of the local population. Children, their parents and young people must be involved in relation to decisions regarding individual support and local provision.

All Together Better, a group of parent/carers of children and young people with additional needs and the Local Authority, have worked together to develop co-production good practice standards.

5. Who is a Carer?

Some people may not even recognise themselves as a carer, they are a husband, wife, son, daughter, relative or friend of someone who needs their help. We recognise a carer as someone who helps another person on an unpaid basis, usually a relative or friend, in their day to day life. This is not the same as someone who provides care professionally or through a voluntary organisation.

Adult Carers

Adult carers provide, or intends to provide, 'necessary' care for another adult who has care and support needs.

'Necessary' care means activities that the person requiring support should be able to carry out as part of normal daily life but is unable to do so because of their care and support needs.

If the carer is providing care and support for needs that the adult is capable of meeting themselves, the carer is not providing 'necessary' care and support.

Young Carers

The term 'young carer' refers to:

Children and young people under 18 who provide, or intends to provide, care for another person (but excluding paid/ formal volunteers).

Although many young carers would not choose to stop caring, it can have a detrimental effect upon their health, well-being and life chances.

- One in 12 young carers is caring for more than 15 hours per week;
- Around one in 20 misses 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 e.g. the difference between nine B's and nine C's;
- 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;
- Young adult carers (age 14-25) are 4 times more likely to drop out of college or university than students who are not young adult carers;
- Young carers are 1.5 times more likely than their peers to be from black, Asian or minority ethnic communities, and are twice as likely to not speak English as their first language;
- Young carers are 1.5 times more likely than their peers to have a special educational need or a disability; and
- The average annual income for families with a young carer is £5000 less than families who do not have a young carer.

Parent Carers of Disabled Children

A parent carer is an adult who provides, or intends to provide, care for a disabled child for whom the adult has parental responsibility.

The Local Authority must assess:

- Whether a parent carer has need for support and if so what those needs are;
- Whether the disabled child cared for has needs for support; and
- Whether it is appropriate for the parent carer to provide care for the disabled child in the light of the parents needs for support other needs and wishes.

A parent carers' needs assessment must also consider:

- The wellbeing of the parent carers; and
- The need to safeguard and promote the welfare of the disabled child cared for and any other child for whom the parent carer has parental responsibility.

Wellbeing has the same meaning as applies to carers of adult in the Care Act 2014.

In addition a Local Authority must carry out an assessment when a young carer, child, or carer of a disabled child becomes 18 and it considers that there would be significant benefit to the individual.

6. Carers in North Tyneside

The 2011 Census identified 22,208 adult carers in North Tyneside and highlighted a 19% increase in the number of people who are caring for more than 20 hours: the point at which caring starts to significantly impact on a carer's health and wellbeing and their ability to have a life alongside caring.

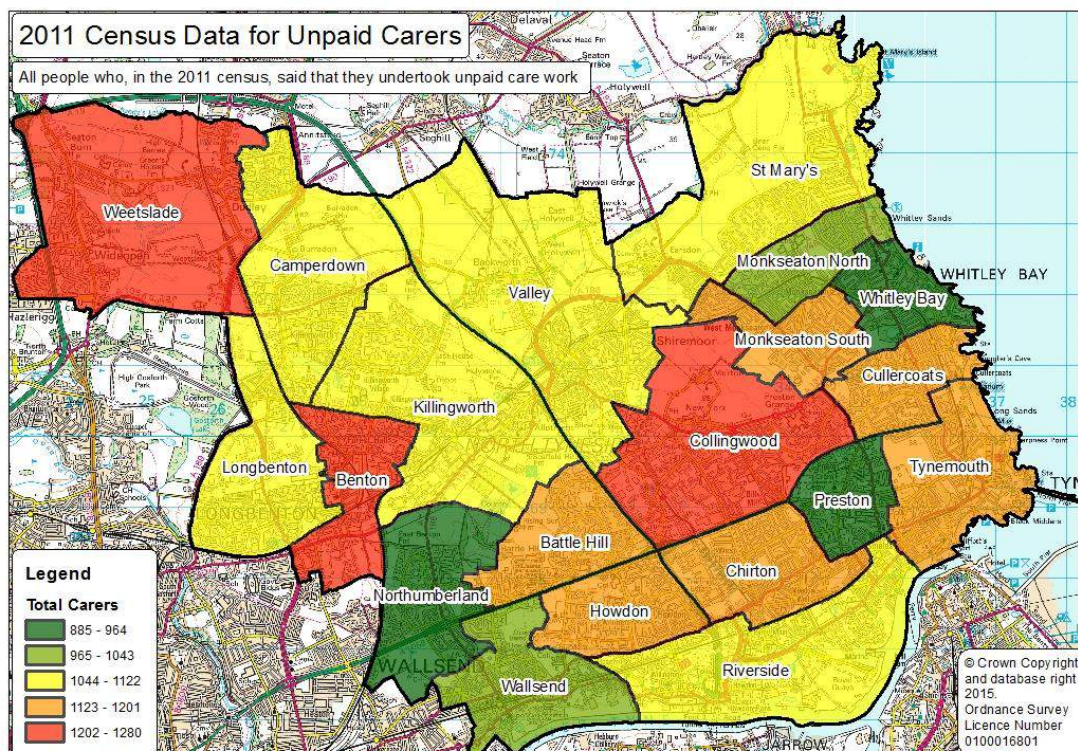
The Census included a question (for each member of each household) that asked:

Do you look after, or give any help or support to family members, friends, neighbours or others because of either:

- Long-term physical or mental ill-health/disability?
- Problems related to old age?

The distribution of people from north Tyneside who replied "Yes..." is shown on Figure 1 below:

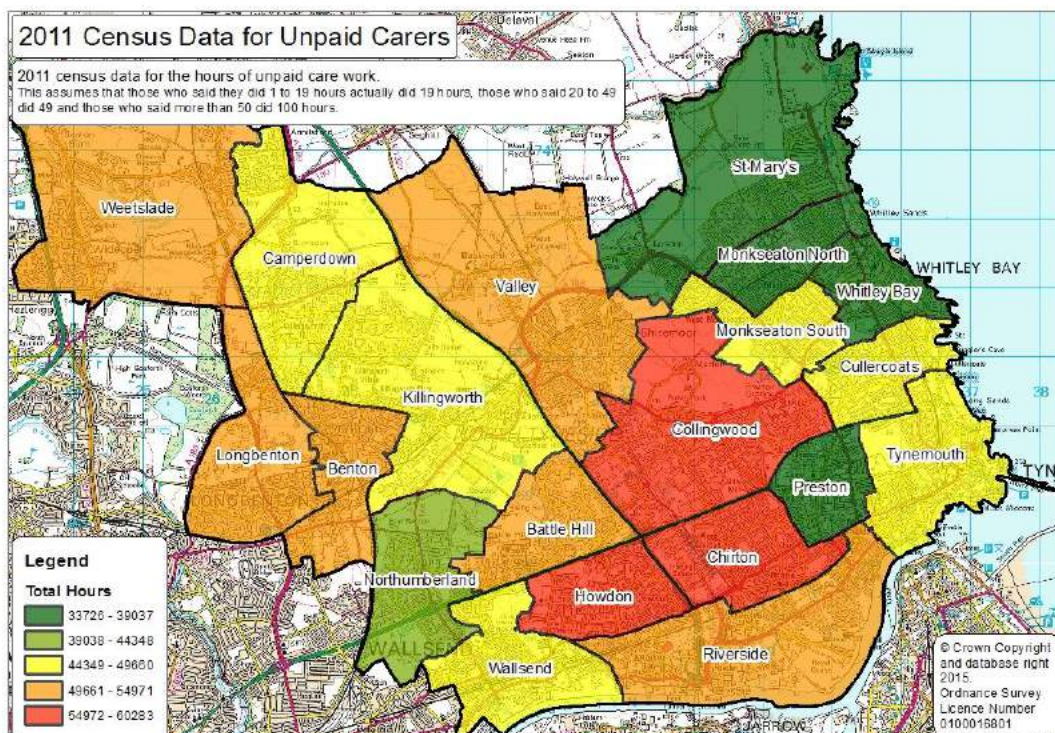
Figure 1



Number of people providing 1-19 hours of unpaid care	13,789
Number of people providing 20-49 hours of unpaid care	2,941
Number of People providing 50+ hours of unpaid care	5,478

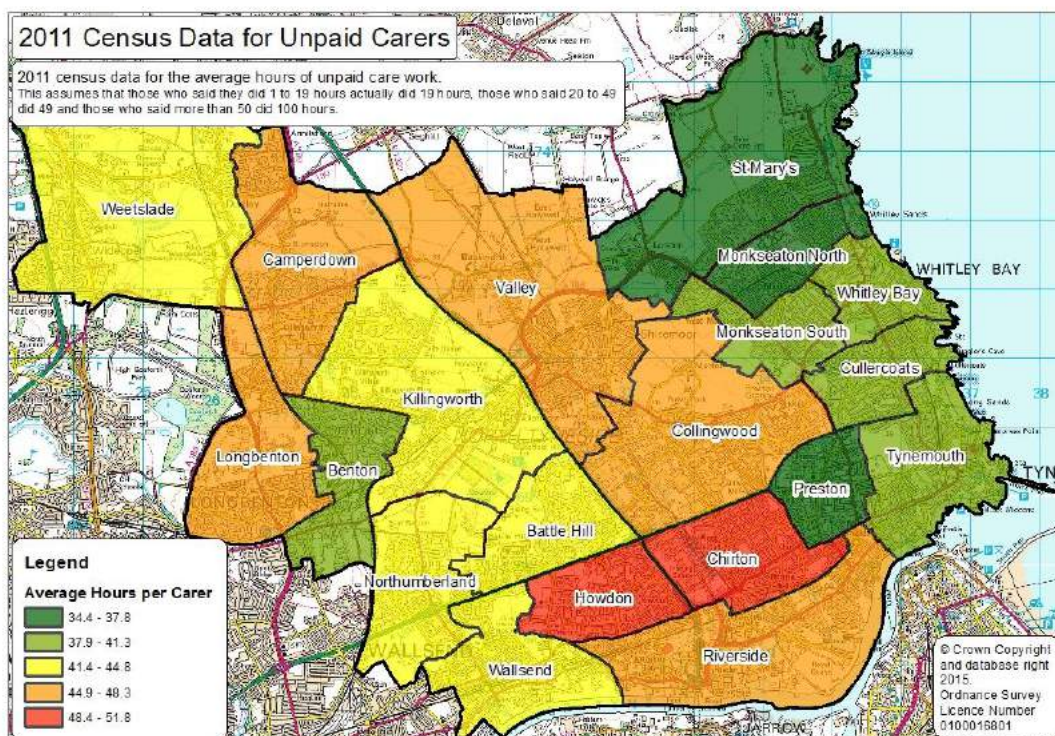
If we assume that those who answered “Yes, 1-19 hours a week” provided care for 19 hours each week, those who answered “Yes, 20-49 hours a week” provided care for 49 hours each week and those who answered “Yes, 50 or more hours a week” provided care for 100 hours each week, then we can estimate the total hours of carer support. The distribution of hours of care is shown in Figure 2 below:

Figure 2



The difference between the two maps comes because some areas have relatively high numbers of carers doing relatively low number of hours. The average number of hours per carers gives this pattern shown in Figure 3 below:

Figure 3



It is recognised that data available on the number of young people providing care is likely to be an under representation of the reality. This is due to various reasons including: families wanting to manage alone; not recognising the caring role of young people; and fear of involvement from services.

425 young carers are known to North Tyneside Carers' Centre, of which 55% are girls and 45% are boys. This is representative of the gender split in young carers in England & Wales.

Carers with 'Eligible' Needs

In considering whether an adult carer has eligible needs, local authorities must consider whether:

- The needs arise as a consequence of providing necessary care for an adult;
- The effect of the carer's needs is that any of the circumstances specified in the Eligibility Regulations apply to the carer; and
- As a consequence of that fact there is, or there is likely to be, a significant impact on the carer's wellbeing.

The Eligibility Regulations state the impact on the carer must be that either:

- Their physical or mental health is at risk of getting worse; **or**
- They are unable to achieve at least one of the following outcomes:
 - look after any children you have responsibilities for;
 - provide care to any other person;
 - maintain their home in a fit and proper state;
 - eat properly and maintain proper nutrition;
 - maintain and develop relationships with family and friends;
 - take part in any work, education, training or volunteering they may wish to;
 - making use of community facilities; and
 - engaging in social activities, hobbies etc.

In considering whether or not a carer can achieve these outcomes, the council must take into account any difficulties a carer has. A carer will be considered unable to achieve the outcome if they:

- Need assistance to achieve the outcome;
- Can achieve the outcome unaided but experience pain, distress or anxiety; or
- Can achieve the outcome unaided but doing so endangers them, or may endanger another person's health and safety.

Eligible needs for adult carers can then be met by providing:

- Advice and/or information or supporting a carer to make use of community resources; and/or
- Replacement care such as respite directly to the cared for person. This would be provided using the cared for person's personal budget; and/or

- A Carers' Personal Budget

Eligible needs for parent carers (dependent upon the complexity of needs assessment) can then be met by providing:

- Advice and/or information or supporting a carer to make use of community resources; and/or
- Child care support; and /or
- Access to Specialist commissioned resources / Personal Budgets

Eligible needs for Young Carers can be met by providing:

- Advice and/or information or supporting a carer to make use of community resources; and/or
- Access to commissioned resources from the Carers' Centre

7. Funding and Services to Support Carers

The North Tyneside Better Care Fund plan includes £560,000 for carer support.

The Council and CCG provide direct funding to organisations that support carers in a number of ways this includes:

Amount (per annum)	Purpose
£ 73,394	North Tyneside Carers' Centre to provide information and advice
£ 19,373	North Tyneside Carers' Centre to fund strategic work
£ 81,308	Two Carer Support Workers who are employed by the Carers' Centre and work in Adult Social Care
£ 30,332	Specialist Mental Health Carer Support Worker (Carers' Centre)
£ 36,093	Young Carers Project Manager (Carers' Centre)
£117,700	Memory Support Service which provides support to people with dementia and their carers (Northumberland, Tyne and Wear NHS Trust)
£104,994	P.R.O.P.S North East – (Positive Response to Overcoming Problems of Substance misuse) to support carers/family members of all ages who care for drug and/or alcohol users in North Tyneside
£463,194	Total amount for direct carer support services

See [Appendix 2 - Commissioned Services](#) for additional information.

Adult Carers

Support for adult carers is often provided by the provision of replacement care and services to the cared-for person. This can include respite breaks, day services and sitting services.

The following activity information relates to the numbers of people accessing a range of different respite services during 2014/15:

Client group / service area	Number of People
Day Services	109
Sitting Services	174
Older people respite	401
Physical disability respite	21
Mental health respite	19
Learning disability respite	66
Total	790

Carers Personal Budgets

Where eligible needs are identified, carers are also entitled to a Personal Budget in their own right. The money can contribute towards, or support the carer to have a break from caring. This may also be used to obtain goods or pay for activities to meet specified outcomes the carer has identified during their assessment.

A pilot to test out the use of personal budgets for carers was conducted during 2013/14. Carers reported that having access to an amount of money in their own right helped them physically and emotionally. They also reported that it gave them a feeling of being appreciated. Following the success of the pilot, personal budgets were made available to all adult carers with eligible needs from April 2015, following a Carers Wellbeing Assessment.

Miscellaneous Support

The council **Adult easeEXTRA** card offers carers some respite for themselves to attend council leisure sites at a priority rate.

The **Carer Emergency Card** is available for carers to help in times of crisis. For those registered, the council holds a bespoke emergency plan and will respond to a request for help at any time of day.

There is a wide range of **Assistive Technology** which can support carers. This includes equipment to monitor the cared for person and keep them safe.

Carers have access to **free** or **discounted** courses through the **Adult Learning Alliance**.

Supporting Carers in Employment

In 2014 the Department of Health, Department for Work and Pensions and Government Equalities Office agreed to jointly funding the Social Care Institute for Excellence (SCIE) to work with local authorities to develop some local pilots exploring how carers can be supported within their local communities to remain in work alongside their caring responsibilities. North Tyneside Council in partnership with the North Tyneside Carers' Centre submitted a bid and was successful in securing project funding of £147,882 for two years from April 2015.

The purpose of the project is to build on the existing work to date, and also to test out new ways to reach more carers who are struggling to juggle employment and their caring responsibilities. It will also provide the opportunity to engage with a number of local employers (including the Council) and work with them so that they understand carers' rights, the problems carers face and how using a flexible working approach can achieve impressive business results.

The learning from this project will support the delivery of this plan.

Parent Carers of Disabled children ([see Local Offer, Short Breaks Services Information Statement](#))

Children and families can access universal services directly to provide them with short break opportunities. Some children and families will require targeted services. Those children and families with the most complex disabilities will require specialist short break services.

Targeted services include:

- North Tyneside Carers' Centre for Parent Carers and Young Carers;
- Pathways Youth Clubs and holiday activities for families; and
- Shiremoor Adventure playground.

Specialist services are provided to children and young people with complex disabilities, these include:

- Addison Street short break unit;
- Outreach and school holiday provision; and
- Personal Budgets to purchase their own support services.

8. What Carers Have Told Us

A significant amount of consultation with carers has helped us to agree the priorities in this document, this includes; focus groups with adult and young carers; on line surveys; Adult Social Care Carers Survey; sessions held by Healthwatch North Tyneside; and feedback from members of the Carers' Voluntary Sector Forum and the All Together Better group.

Many carers are very positive about the help and support they have received from health and social care professionals, and also providers of services that support carers. We do know, however, that the support received is not always consistent and there are areas we need to improve on.

Summary of Consultation

Healthwatch North Tyneside

Healthwatch North Tyneside invited carers to share their experiences through focus groups, discussions and an online and paper survey.

Through their work they gathered experiences from 70 people caring for 86 children and adults and identified some of the unpredictable impacts that caring can have on carers' lives. Many carers described feeling they had to battle with services and often lacked information and advice, involvement in care planning and discussion about their needs within their caring role.

A number of themes emerged from the consultation:

1. The unpredictable and profound impacts that caring responsibilities have on the lives of carers and the struggle for their needs to be taken into account;
2. The battle carers perceive themselves to be having with statutory services;
3. Significant unmet need for emotional support;
4. Significant unmet need for information and advice;
5. The value of peer support and informal networks; and
6. Lack of involvement in care or service planning.

As a result of this work Healthwatch identified three priorities for action:

1. Clarify what information, support and services are available to carers, whether assessed as eligible for service input or not, and what steps carers can take to access these, with services promoting this information more proactively, including through training for frontline staff;
2. Promote options for emotional support, carefully reviewing the places people are likely to look (online and offline) early on in their caring experience. This support is desperately needed, but some good options exist already; and
3. Prioritise the development and implementation of the Quality Monitoring Tool, referenced in the 2012-14 Strategy incorporating the Carers' Charter and use this to ensure carers needs are being identified, listened to and acted upon, as well as to assess the wider quality of services.

The full report can be accessed via Healthwatch North Tyneside website.

[Carers: Healthwatch North Tyneside](#)

Make a Difference Comments Cards

46 carers completed a comment card between July and September 2014.

We asked adult and young carers what one thing would make a difference to them. The comments can be broadly grouped as follows:

- More support – professionals who do what they say they will do
- Employment issues – greater understanding by employers
- Improved financial support
- Provision of emergency and crisis support
- Support on legal matters
- Co-operation and communication between professionals
- Recognition for carers, particularly from professionals. Also people having a better understanding of carers difficulties
- Education - better support in schools
- Specialist services to support carers including those that are condition specific.

Carers Strategy Six Priorities Survey November – January 2015

From the Adult Carers Strategy 2012-14 we identified six of the original ten priorities which were still relevant and appropriate to take forward ([see page 23 for information](#)). We asked carers to tell us if the priorities identified were right and if so, what they would like to see happen. 39 responses were received.

We asked:

Do you think the six priorities we have identified are still relevant?

Is there anything missing?

If you think the priorities are right, what actions would you like to see taken forward?

39 people responded to the survey. All respondents thought that the identified priorities were still relevant.

The key points from the additional comments and actions were:

- The provision of good advice and information was seen as very important by the majority of carers. Some people said they weren't aware of what help and support was available;
- Opportunities to meet other carers who are in the same position was identified as something that would help carers;
- The need for more understanding by GP's and professionals who can appreciate that the carer has needs too. One carer said *"Mine see me as Mum only"; and*
- The need for regular respite and a break from caring was highlighted *"who cares for the carers?"*

People were also asked what stops them from accessing any support. Many carers said they were just too busy or exhausted from their caring role and others said that they were just used to coping.

Adult Social Care Outcomes Framework (ASCOF) Carers Survey (November 2014)

The ASCOF measures how well care and support services achieve the outcomes that matter most to people. A survey of carers is carried out every two years. In November 2014 we included some additional questions to the standard questions that were required. The survey was sent to 1155 carers who were known to Adult Social Care and 436 responses were received.

Key findings:

- Satisfaction with social care services has improved by 2.1 percentage points but...;
- Carer reported quality of life is worse than 2 years ago;
- Carers feel less included or consulted in discussion about person they care for; and
- The percentage of carers finding it easy to find information about services fell by 10 percentage points.

ASCOF: Measure	2012/13	2014/15	Regional average
1D: Carer-reported quality of life**	8.7	8.3	8.4
1I2: The proportion of carers who reported that they had as much social contact as they would like	50.5%	45.3%	46%
3B: Overall satisfaction of carers with social services	41.3%	43.4%	49.6%
3C: The proportion of carers who report that they have been included or consulted in discussion about the person they care for	79.5%	74.6%	79%
3D2: The proportion carers who find it easy to find information about services	76.3%	65.9%	72.7%)

**The measure 1D gives an overall score based on respondents' self-reported quality of life across six questions in the survey. All six questions are given equal weight.

Additional Information

- 18% of carers have had to give up work due to caring;
- 68% of carers feel caring has made their own health worse (16% 'A lot worse'); 18% miss their own health appointments; 11% carers have suffered a physical injury due to caring;
- 70% of carers are not aware they are entitled can have a separate carers assessment, only 22% recall being offered one;
- 67% of carers who had an assessment were satisfied with it, 7% were dissatisfied;
- 67% of carers said something could be done to help them in their caring role. The most common response by some way was more carer breaks (47%), followed by

- better advice and information (24%), an out of hours crisis response service (8%), counselling (6%), support groups (4%) and training (3%); and
- 57% of carers had reached a 'breaking point' in the last 12 months. The most common outcomes were: sought help from friends or family (29%); Contacted GP, nurse/healthcare professional (25%); Contacted Social Service (16%); Hospital attendance (13%), Emergency services called (8%); Carer contacted Carers' Centre / group (5%).

Carers in Employment

In October 2013 North Tyneside Carers' Centre carried out an online survey targeting carers in employment. The survey highlighted the following issues:

- 60% of respondents weren't aware of Time off for Dependents;
- 48% of respondents said they wanted more information about support networks;
- 30% of respondents said they wanted more information about managing the condition of the person they care for; and
- 39% wanted benefits/financial advice.

Yet 87% of respondents said they hadn't accessed support to help them with work and employment issues.

Children & Young People Consultation

Young carers were consulted with about the North Tyneside Young Carers' Strategy 2010-2013 priorities, to review the progress and relevance, these included:

- Finding ways to help young carers when they first start caring;
- Helping young people to understand what caring means;
- Keeping young carers safe from harm;
- Looking at and understanding what you need and what the person you care for needs;
- Finding ways to help schools understand how caring affects your education and know how to offer support;
- Emphasising the importance of your health. Doctors, nurses and other health staff should give young carers advice about their health;
- Giving you information and advice. For example, this might be about other people that can help you or helping you to learn more about an illness or disability;
- Communicating with you and your family in a way that you find easiest; and
- Keeping in touch with all of the people helping you and your family so people know what's going on.

Young people indicated that the above priorities continued to be important in identifying and supporting young carers.

Parent/Carers of Disabled Children

Feedback from a meeting between All Together Better and the Principal Manager, Additional Needs and Disability included:

- Training of GP's required to assess the needs of parent carers;
- Ensuring the Local Offer is clear regarding the process by which an assessment of the needs of parent carers is obtained;
- Ensuring the Local Offer is clear in relation to the resources available for parent carers;
- Ensuring the Local Offer is clear in relation to the way in which parent carers can ask for an assessment by Adult Services to support transition into adulthood;
- Parents wish be trained to meet the needs of children;
- Parents must stop being considered " bad parents";
- Increase opportunities to help parents help themselves; and
- Supporting parent carers into work and create opportunities that use their specialist knowledge.

Priorities

The North Tyneside Commitment to Carers is based upon six priorities:

1. Earlier identification of carers and the provision of quality information;
2. Improved communication;
3. Improved carer health, wellbeing and support;
4. Support that enables carers to go to/continue to work or in education;
5. Carers have access to emotional support; and
6. Smooth transition of support from children's to adult services.

Safeguarding all carers will be an overarching priority that we will consider throughout this work.

A two year Action Plan has been developed to accompany this document. The plan outlines the key actions that will be taken to address each of these priority areas; however a summary is shown below. This plan will be reviewed and updated as necessary in 2016.

Priority 1 - Earlier Identification of Carers and the Provision of Quality Information

What carers have told us is needed

- Good quality information at the point of need
- Additional help for carers who are new to the caring
- More training for health and care professionals so that they understand carers needs and are able to give consistent information

- The Carers Charter was a good starting point but services need to demonstrate how they are embedding the principles across their service
- Find ways to help young carers when they first start caring
- Helping young people to understand what caring means
- A clear Local Offer for Parent Carers regarding:
 - an assessment of their needs;
 - the resources available for them; and
 - the way in which they can access an assessment to support transition into adulthood.

What we will do

1a. Quality Information

- Increase opportunities for carers to find out what is available to support them
- Ensure good quality information is available at key points of access
- Update the Carers' Guide to Health and Wellbeing

1b. Early identification of carers

- Ensure a targeted workforce is trained to recognise adult, young carers and parent carers Education, Health and Care
- Ensure the views of the young carers are incorporated into Early Help Assessment / Child in Need Assessment
- Ensure that appropriate training is available for health and social care professionals
- Ensure carers of people being discharged from hospital are identified & supported
- Introduce Quality Assurance processes across Children and Adult Services to ensure that carer needs are identified and met during assessment and review processes

Priority 2 - Improved Communication

What carers have told us is needed

- Better communication between health and social care
- More information about what is available for carers
- Care providers to recognise carers
- Opportunities for carers to give their views on services and for commissioners to listen to carers
- Information for young carers about services/professionals that can support young people or provide information about specific illnesses/disabilities

What we will do

- Ensure that carers are seen as expert partners in care by:
 - Re-launching the Carers Charter and recruit more Carers' Champions

- Develop a self-assessment tool for North Tyneside Council, North Tyneside CCG and providers to measure their progress against the Carers' Charter and build this into quality monitoring processes
- Develop processes to evaluate carers' experiences of assessment.

Carers also told us it was important to have a named worker to support them. It is difficult to tell from the feedback whether carers require this for themselves or for the person they care for. We need to ensure that people are well informed about where and how to access support when it is needed, either for themselves or for the person they care for.

Priority 3 - Improved Carer Health, Wellbeing and Support

Without the right support in place, carers often find their own health and wellbeing suffering as a result of the care they provide.

What carers have told us is needed

- "Someone to care for me"
- More preventative support before carers reach breaking point
- More flexible respite provision
- Better information about the services that are available to support carers
- Opportunities for young and adult carers to have a health check
- Provision of replacement care to attend carers events
- Support in times of crisis
- Specialist activities for young carers to improve wellbeing and health i.e. leisure activities etc.
- Fully understanding what young carers and the person they care for needs

What we will do

- Targeted work with GP's and other health professionals
- Increase opportunities for carers to access breaks
- Explore options for crisis response for carers
- Explore assistive technology options to support carers
- Improve support for carers of people with mental health problems
- Support carers to understand the importance of safeguarding adults and children

Priority 4 - Support that Enables Carers to go to/Continue to Work or be in Education

What carers have told us is needed

- A fair assessment for carers and support with the assessment
- More support so we can continue to work

- Better links with the Jobcentre Plus and Adult Learning Alliance
- Employers to actually obey the rules
- Employers to have a better understanding of carers rights
- More information about alternative education and how to access it
- Providing information and support to young carers about options other than caring once they have left education
- Schools to understand why young carers may struggle with their education
- Support for young carers in mainstream education

What we will do

- Ensure that young carers are supported/enabled to access the same opportunities as their peers
- Explore options to enable parent carers to access training and employment
- Raise awareness of support available to return to employment
- Explore options to support carers to remain in employment by using the learning from the Supporting Carers in Employment Project.

Priority 5 - Carers have Access to Emotional Support

What carers have told us is needed

- Access to peer support groups
- GP's to be trained regarding signposting
- More access to emotional support opportunities
- Courses to help carers have a better understanding of the condition of the person they care for
- Increased opportunities to help parent carers to help themselves
- Quick access to support – long waiting times often make a difference between coping and cracking
- Access to counselling
- Access to support groups where you can discuss topics such as legal matters etc.
- Emotional support services for young carers
- Opportunities to meet with other young carers

What we will do

- Review the current range of services and support that is available to ensure it is appropriate
- Strengthen our approach to assessing carers needs and monitor the quality of the support that is provided
- Ensure carers can access emotional support

Priority 6 - Smooth Transition of Support from Children's to Adult Services

What carers have told us is needed

- Services that are in place in good time, not last minute (if at all)
- More information for young carers so that they understand what help is out there

What we will do

- Ensure that young carers receive quality information, advice and support to assist their transition into adulthood
- Develop support options for 16-25 year olds with caring responsibilities
- Develop the protocol to ensure the effective transition for disabled children into Adult Services

Additional work needed to support this plan

There are a number of things that we need to do to support the delivery of this plan including:

- A review of the Memorandum of Understanding between Children and Adult Services in light of the Care Act and Children and Families Act to ensure that services work together to support carers
- Developing systems that will improve our knowledge of adult, young carers and parent carers through the collection and analysis of information
- A review of services and support that is available for all carers to make sure it meets their needs
- A review of advocacy support for carers

Next steps

A steering group has been established to oversee this work. This consists of commissioners from North Tyneside Council and the North Tyneside Clinical Commissioning Group and the Carers' Centre. All organisations involved are fully committed to delivering this plan and will ensure the plan is adopted and the relevant people are held accountable.

Additional task and finish groups will be established to progress each priority and area of work that has been identified in the action plan. The chairs of each group will be required to report on progress to the steering group. A reference group of carers will be established to support this work.

North Tyneside Carers' Charter

This charter is a set of principles agreed by carers in North Tyneside to promote better recognition and support for them

Recognising Carers

- Recognise the contribution I make to society
- Recognise the impact of caring on me
- Recognise my expertise
- Take my needs into consideration
- Recognise that I have a life of my own outside of caring and may have other commitments

Valuing Carers

- Listen to what I have to say
- Respect my views
- Show me you care about me and my needs, as well as the person I care for
- Ensure equality of access to all services

Information and Advice

- Give me information in a timely manner
- Check that I have fully understood and been able to take on board what you have told me
- Make me aware of my rights and what I am entitled to
- Advise me how to access support and services

Involving Carers

- Involve me in assessments, care planning and reviews
- Offer me meaningful and timely involvement
- Involve me in decisions about the person I care for
- Be flexible and offer meetings at times which meet my needs
- Feedback to me so I know the outcome of my involvement
- Involve me when you make changes and/or develop new services
- Respect confidentiality but don't use it as a barrier to involving me



North Tyneside Council

This work is supported by the
Carers' Voluntary Sector Forum.
For more information contact the
Carers' Centre:

Telephone: 0191 643 2298
e mail: claire.easton@ntcarers.co.uk



NHS North Tyneside
Clinical Commissioning Group

Appendix 2 – Commissioned Services



North Tyneside
Carers' Centre

North Tyneside Carers' Centre

North Tyneside Carers' Centre understands the demands of providing unpaid care and knows how exhausting the carer's role can be. The professionally trained team offer **information, advice and guidance** which are individually tailored to meet the individual's needs.

SUPPORT PROVIDED

North Tyneside Carers' Centre offers a wide range of services including:

- Emotional support
- Practical support
- Advocacy
- Benefits advice
- Training to help carers, such as handling a wheelchair or dealing with aggressive behaviour
- Regular newsletters and information about local and national issues affecting carers
- Support through the carer assessment process
- Support for carers in employment or those wishing to return to employment or training
- Peer support groups (including dementia and mental health)
- Social activities and events
- Counselling
- Caring and Wellbeing Forum
- Aromatherapy
- Young Carers' Project

CONTACT INFORMATION

The centre is open from 9:00am – 5:00pm Monday to Friday. On the 2nd Tuesday and 4th Thursday of each month the centre is open until 8pm.

Telephone: 0191 643 2298
Website: www.northyntsidecarers.org.uk
Email: enquiries@ntcarers.co.uk



PROPS North East Service Provision

PROPS North East provide support to carers/family members of all ages who care for drug and/or alcohol users within Newcastle and North Tyneside. Types of support identified can present as emotional, practical, social, health-care, financial and/or legal difficulties.

PROPS North East's broad range of free services provided is through confidential outreach work via one-one support, group work, counselling, drug and alcohol awareness, behavioural couples therapy, family mediation, education and training, respite opportunities, welfare rights support, complementary therapies and a confidential out of hours helpline.

Referral into PROPS North East can be made by the individual or by a professional through an initial telephone call to the office.

PROPS offer 1-1 or within a group setting an 8 week training programme "How to help your loved one – Alternatives to Nagging, Pleading and Threatening" (Community Reinforcement & Family Training) formally known as CRAFT. This programme offers carers and family members' emotional support and practical skills in the following:

- Drug & Alcohol Awareness
- Understanding Using Behaviour
- Reducing Conflict
- Positive Communication Skills
- Steps to Influence Change
- Ensuring you take care of your own needs

Current groups running in North Tyneside are:

SMART Family & Friends (CRAFT Maintenance): Thursday 1-3pm, Children Centre, Wallsend (fortnightly)

SMART Family & Friends (CRAFT Maintenance): Wednesday 5.30-7.30pm, NTRP Oak Trees, North Shields (fortnightly)

Young Persons' Group: Tuesday 4.00-6pm The Bungalow, Children's Centre, Howdon (weekly in term time). The summer programme – Friday 10am-2pm, Meeting at Tynemouth Metro (weekly)

CRAFT Training Programme - Daytime: Tuesday 10am-12pm – Children Centre, Wallsend (weekly)

CRAFT Training Programme - Evening: Thursday 6-8pm – PROPS North East, Linskill Centre, North Shields (weekly)

Email: northtyneadmin@propsnortheast.org.uk

Tel Number: 0191 270 4248

Helpline Number: 0191 226 3440 Mon-Fri – 5pm-9pm & weekends 9am-9pm

Website: www.propsnortheast.org.uk

Northumberland, Tyne and Wear 
NHS Foundation Trust

The Memory Support Service (MSS)

The Memory Support Service (MSS) is available to anyone living in North Tyneside who has a diagnosis of dementia or has concerns about a memory problem. The service also supports carers.

Relevant information may be given in a range of ways such as:

- one to one discussions
- education sessions
- by attending a forum
- a personal information pack.

The Memory Support Service is staffed by registered nurses and an experienced support worker, all with considerable knowledge and expertise in dementia. Their role is to act as a point of contact throughout the duration of the illness. The Memory Support Service will enable access to a network of services, assisting people to navigate their way to the right help, at the right time, in the right place.

Contact details

North Tyneside Memory Support Service
Sir G. B. Hunter Memorial Hospital
The Green
Wallsend
Tyne and Wear
NE28 7PB
Tel: 0191 220 5985

The Service is available during normal working hours Monday to Friday 9am - 5pm.

Appendix 3 - Other local services that can support carers



Vision

A world where everyone enjoys later life

Mission

To help people make more of life

Contact details

Age UK North Tyneside
Bradbury Centre
13 Saville Street West
North Shields
Tyne & Wear
NE29 6QP

Tel: 0191 280 8484

Fax: 0872 110 8450

Email: enquiries@ageuknorthtyneside.org.uk

Website: www.ageuk.org.uk/northtyneside



LD:NorthEast believe that people with learning disabilities should have the same rights, opportunities and quality of life as everyone else.

The organization is dedicated to supporting people with learning disabilities, and their carers, to lead fulfilling lives.

Contact details

205 Park Road
Wallsend
Tyne and Wear
NE28 7NL

Tel: 0191 262 2261

Fax: 0191 263 4835

Email: info@ldne.org.uk



SIGN – North Tyneside is a network of providers of free, independent and confidential information working to put people in need of practical or emotional help and guidance in touch with those local organisations best able to provide it.

SIGN Members

Age UK North Tyneside

Bradbury Centre, 13 Saville Street, North Shields
(0191) 280 8484

www.ageuk.org.uk/northtyneside

Community & Healthcare Forum

205 Park Road, Wallsend
(0191) 295 4233

www.chcfnorthtyneside.org.uk

Disability North

The Dene Centre, Castle Farm Road, Newcastle
(0191) 284 0480

www.disabilitynorth.org.uk

Independent Advocacy North Tyneside

62 Howard Street, North Shields
(0191) 259 6662

www.iant.org.uk

Learning Disability North East

205 Park Road, Wallsend
(0191) 200 1100

<http://www.ldne.org.uk/>

North Tyneside Adult Social Care Gateway Team

Quadrant West, Silverlink North, Cobalt Business Park
(0191) 643 2777

www.northtyneside.gov.uk

North Tyneside Carers' Centre

Floor 3, YMCA Building, North Shields
(0191) 643 2298

www.northtynesidecarers.org.uk

North Tyneside Citizens Advice Bureau

St Lukes Church House, Hugh Street, Wallsend
51 Bedford Street, North Shields

0844 499 1198

www.ntcab.org.uk

North Tyneside Coalition of Disabled People

Room P174, North Tyneside General Hospital,
Rake Lane, North Shields
(0191) 296 1437

www.ntcdp.co.uk

Skills for People

Key House, Tankerville Place, Jesmond
(0191) 281 8737

www.skillsforpeople.org.uk

Care and Connect

Care and Connect is a new service in North Tyneside for adults to provide advice and support to stay independent. Support is provided by telephone or face to face in community settings.

The Service offers tailored and detailed knowledge of the local care and support system and information and access to the Council's adult social care system, where needed.

You can contact **Care and Connect** by:

- Calling into **Wallsend Customer First Centre**
- Telephone 0191 6437474
- Email Care&connect@northtyneside.gov.uk

North Tyneside Council's Gateway Team

The Gateway Team is the first point of contact with Adult Social Care. They provide free advice, information and a signposting service to everyone.

Tel: (0191) 643 2777. Available Monday to Thursday 8.30am to 5pm and Friday 8.30am to 4.30pm.

For urgent, out of office hours support, **that cannot wait until the next working day,**

Tel: (0191) 200 6800.



Front Door Service – this is the main central access point that is used by families to access social care support. From this access point a family will either be signposted to the opportunities available through the Local Offer or referred for further support to the Early Help and Assessment Team. Tel: 0345 2000 109

If you have a concern about the safety or welfare of a vulnerable adult in North Tyneside, please get in touch with the Gateway Team.

If you have concerns about the safety or welfare of a child in North Tyneside, the Front Door Service is the first point of contact for all families, children and professionals.