



**Newcastle Gateshead
Clinical Commissioning Group**

Caring about Carers Conference Conference Report

February 25 2015



Transforming lives together >



The Caring about Carers conference was co-produced by NHS Newcastle Gateshead CCG, Newcastle City Council, Newcastle Carers, Barnardos, the Elders Council, Mental Health Concern, North of England Commissioning Support Unit and the Quality of Life Partnership.

Involve North East are an independent involvement and engagement organisation who work with patients, communities and harder to reach groups to gain insight into designing high quality, responsive and cost effective services.

All the feedback from the conference was analysed by Involve North East who have produced this report on behalf of Newcastle CCG and Newcastle City Council. The information contained within this report will feed directly into ensuring that the CCG and Local Authority jointly commission services to meet the needs of carers.

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Executive Summary

1.0 Introduction

On Wednesday 25th February 2015, NHS Newcastle Gateshead Clinical Commissioning Group (CCG), formerly NHS Newcastle West and NHS Newcastle North and East CCGs, held a Caring about Carers Conference. The conference was planned and co-delivered by the CCGs, Newcastle City Council and partners from the community and voluntary sector.

1.1 Purpose and outcomes

The overall purpose of this conference was:

- To raise awareness of the work of carers, their contribution to the health and social care agenda and the issues they face.
- For the audience to identify ways they, as individuals and organisations, can tackle the known and understood issues and concerns faced by carers in their everyday lives, taking into account other health and social care issues that may exist.
- For the feedback from the workshops to be fed into the specification for carers services, for example, what is good and what needs to change.

The key outcomes of the conference were to:

- Recognise the responsibilities and challenges our carers face and our responsibility to support them.
- Learn 'what good looks like' in terms of carers support within all organisations.
- Identify and commit to practical actions which will help address the issues raised through the conference.
- Identify key themes and objectives to be considered as part of the development of a carer's strategy for Newcastle.

1.2 Context

"A carer is someone who provides unpaid care and support to a family member, friend, partner or neighbour who has a disability, has an illness, is frail, has mental health difficulties or has alcohol or drug related problems."

The 2011 Census found that 5.4 million people in England were providing unpaid care with over a third providing 20 or more hours care each week. The Census also found that there were over 166,000 young carers aged 5-17 in England.

There are a range of national policy documents which have, over a number of years, identified key principles to be achieved for the care of carers. Key documents include the National Carers Strategy (2008) and Recognised, valued and supported: Next steps for the Carers Strategy' (2010). The Care Act 2014, new legislation coming into force in April 2015, is also important in making care and support clearer

and fairer.

In Newcastle, within their Locality Commissioning Plan for 2013/14-2015/16 NHS Newcastle West CCG identified “Support to carers” as a specific project within their plan on a page, linking to national NHS policies. NHS Newcastle North and East CCG, also within their Locality Commissioning Plan for 2013/14-2015/16, identified Whole system transformational programme – older people with complex health and social care needs” as a change initiative with an outcome of “Increased awareness of carers’ issues and strategies to better support carers in their caring role”.

1.3 Attendees

One hundred and thirty two people attended the Caring about Carers Conference (for a full list of attendees, see Appendix 1). Attendees came from a range of sectors including health and social care, service providers and commissioners from the voluntary and community sector, education and a number of patient representatives and carers.

2.0 Conference programme

The structure of the conference consisted of a range of speakers in the morning, including a theatre performance and a film, and a range of workshops focused on different topics in the afternoon followed by a panel discussion. For a full programme of the event see Appendix 2.

The presentations and information from the conference can be viewed at the links below:

<http://www.newcastlegatesheadccg.nhs.uk/caring-about-carers-conference-developing-good-practice-across-newcastle/>

2.1 Keynote speaker

2.1.1 Ewen Weir, Director of Wellbeing, Care and Learning, Newcastle City Council

Ewen was the keynote speaker. He provided a strategic perspective to thinking about carers. The key theme from the presentation was the breadth of issues that carers have to deal with and the range of challenges this brings, both for carers and for the system supporting carers. The challenges faced by carers, such as ill health, leaving work and financial difficulties, coupled with the insufficient recognition and support from the health and care system, highlight the need for significant changes to be made.

2.1.2 Fiona Richardson, Carers Lead Officer, Newcastle City Council

Fiona spoke alongside Ewen Weir and detailed the journey so far for carers’ legislation and guidance. The presentation outlined the National Carers Strategy developments and the upcoming Care Act 2014. In addition, the Carers Trust ‘hub’ model was described showing what is important to carers. This was used in a

consultation in Newcastle to ask carers what they think is working well and what could be improved and from the consultation the top five key priorities for carers were identified:

1. Carers own health and wellbeing
2. Carers having a break
3. Emotional support and counselling for carers
4. Availability of information for carers
5. Emergency planning and support for carers and the person in need of care

2.3 Dr Raj Bethapudi, GP Carers Champion for the Royal College of GPs (RCGP), GP and Carers Lead for NHS Sunderland CCG

Dr Bethapudi spoke of the role and challenges of general practice in identifying and supporting carers. In his GP Carers Champion role with RCGP, Dr Bethapudi aims to help primary care to support carers, to liaise with GPs to make support for carers more robust; and to link with other VCS organisations.

2.4 Open Clasp Theatre Company

Open Clasp performed an extract from 'Swags and Tails', a production looking at issues affecting older people and carers, entitled 'Living my life: an insight into a life caring for someone'. The performance was set in a care home and the main focus was on May's story, a daughter of one of the residents, who previously cared for her mother at home until the situation worsened and she could no longer cope. After the performance, conference delegates took part in table discussions to show how the various events affected May as a carer.

Following the discussions, Open Clasp led an activity with all delegates to create a human bridge with a carer in crisis at one side and a fully supported carer at the other side. Delegates identified methods of support and decided an appropriate order for those actions, and each person represented part of the bridge.

2.5 Paul Brownlee, Service Manager, Young Peoples Services, Newcastle City Council

Paul highlighted the challenges faced by young carers and the need for services and support. Three key elements were highlighted in relation to young carers including the need for services to work together across organisational boundaries, the need for young carers to have an education and the need for a family-based approach.

A film was shown of Amelia's story, a young carer looking after a family member with a personality disorder. Amelia had been caring for a family member for a number of years and was identified through her school when she began to fall behind with work. Amelia's school provided support and were very understanding of her situation, however, away from school Amelia's social life began to suffer. Amelia could not spend time with her friends because of her caring commitments. Amelia

was introduced to Newcastle Young Carers and they provided a whole range of support so she could lead her own life beyond her caring responsibilities.

3.0 Workshop findings

In the afternoon of the conference, a number of workshops were held that covered the following topics:

- Issues and needs of young carers
- Issues and needs of adult carers
- Carers of older people
- Carers of people with mental health concerns
- Carers and primary care health services
- Carers' issues

In each group, three main questions were asked to gain an understanding of each theme:

1. What is good about carers' experiences within your own organisation?
2. What are the three main change proposals from the conference you will take back into your organisation?
3. What are the three key considerations that health and care need to build into future strategy and services for carers in order to best address the issues raised within conference discussions?

The common themes from the workshops were:

- Early identification and prevention
- Collaborative working
- Information provision for carer issues
- Building relationships with carers
- Reducing carer stigma
- General support for carers
- Accessibility
- Carer's assessments

4.0 Panel discussion

The panel discussion took place at the end of conference and each workshop group submitted a question to be answered by the panel. The panel was chaired by Jill Remnant and included:

- Jackie Cairns, Director of Planning, Delivery and Transformation, NHS Newcastle Gateshead CCG
- Dr Karen Nielsen, Older people's mental health, care homes and dementia lead, NHS Newcastle Gateshead CCG
- Dr Guy Pilkington, Chair NHS Newcastle Gateshead CCG
- Steph Edusei, Chief Executive, Healthwatch Newcastle

- Paul Brownlee, Service Manager, Young Peoples Services, Newcastle City Council
- Fiona Richardson, Carers Lead Officer, Newcastle City Council
- Katie Dodd, Chief Executive, Newcastle Carers

The questions and panel discussion are detailed in Section 4 in the main report.

6.0 Recommendations

It is suggested that NHS Newcastle Gateshead CCG and Newcastle City Council take time to analyse the findings of this research to inform the decision on the future of carers' services and inform future service specifications. From the findings, some recommendations can be made.

The recommendations provide suggestions about the following topics:

- Early identification of carers
- Role of primary care in carer identification and support
- Collaborative working
- Shared information
- Information provision
- Carer's assessment
- Language
- Reducing carers stigma
- Mentors and champions
- General carer support
- Staff training

The full recommendations can be seen in Section 6 of the main report.

7.0 Next steps

The information gathered from the day will be used to inform joint CCG and Local Authority carer strategy and support decisions on the specification for carers in the city.

Section 1 - Introduction

1.1 Introduction

On Wednesday 25th February 2015, NHS Newcastle Gateshead Clinical Commissioning Group (CCG), formerly NHS Newcastle West and NHS Newcastle North and East CCGs, held a Caring about Carers Conference. The conference was planned and co-delivered by the CCG, Newcastle City Council and partners from the community and voluntary sector.

1.2 Purpose and outcomes

1.2.1 Purpose

The overall purpose of this conference was:

- To raise awareness of the work of carers, their contribution to the health and social care agenda and the issues they face.
- For the audience to identify ways they, as individuals and organisations, can tackle the known and understood issues and concerns faced by carers in their everyday lives, taking into account other health and social care issues that may exist.
- For the feedback from the workshops to be fed into the specification for carers services, for example, what is good and what needs to change.

1.2.2 Outcomes

The key outcomes of the conference were to:

- Recognise the responsibilities and challenges our carers face and our responsibility to support them.
- Learn 'what good looks like' in terms of carers support within all organisations.
- Identify and commit to practical actions which will help address the issues raised through the conference.
- Identify key themes and objectives to be considered as part of the development of a carer's strategy for Newcastle.

1.3 Context

1.3.1 National context

"A carer is someone who provides unpaid care and support to a family member, friend, partner or neighbour who has a disability, has an illness, is frail, has mental health difficulties or has alcohol or drug related problems."

The 2011 Census found that 5.4 million people in England were providing unpaid care with over a third providing 20 or more hours care each week. The Census also found that there were over 166,000 young carers aged 5-17 in England.

In 2010, the National Carers Strategy was published, 'Recognised, valued and supported: Next steps for the Carers Strategy'. This strategy built on the 2008 National Carers Strategy. Both documents outlined five key points that must be achieved by 2018:

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

The 2010 Strategy provided further detail, outlining four priority areas:

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

Following from these policies, the Royal College of General Practitioners (RCGP) published 'Supporting Carers: An action guide for general practitioners and their teams'. It outlined the need for general practice to work to identify and support carers with seven actions suggested:

- Identifying a carers' lead
- Finding and recognising adult and young carers
- Involving carers in patient care
- Improving healthcare for carers
- Providing information and support for carers
- Providing specific support to young carers
- Auditing and improving carer support

More recently in 2014, the 'Carers Strategy: Second Action Plan' outlined legal reforms for more flexible working, better integration of health and social care services, better entitlement for all carers and a need to identify more carers.

NHS England, in 2014, also published 'Commissioning for Carers: Principles and resources to support effective commissioning for adult and young carers'. The Principles are a practical tool for commissioners to help them deliver what carers say is important to them. They were developed from research, case studies and

best practice which outlined the issues for carers including poor physical and mental health, financial issues and isolation. Carers also identified what they want including recognition and respect as a carer and thinking about a whole family approach. The principles are:

1. Think Carer, Think Family; Make Every Contact Count
2. Support what works for carers, share and learn from others
3. Right care, right time, right place for carers
4. Measure what matters to carers
5. Support for carers depends on partnership working
6. Leadership for carers at all levels
7. Train staff to identify and support carers
8. Prioritise carers' health and wellbeing
9. Invest in carers to sustain and save
10. Support carers to access local resources

The Care Act 2014, new legislation coming into force in April 2015, is built around people and aims to make care and support clearer and fairer, for example, it gives carers equal rights alongside the person they are caring for.

In practice, the Care Act 2014 will outline a duty to identify carers, provide assessments and decide eligibility for support from the local authority. Local authorities will also work with the carer to agree a support plan and provide a personal budget. The Act also gives local authorities the power to charge carers for the support they receive but Newcastle City Council have so far said they would not do so.

1.3.2 Local context

Within their Locality Commissioning Plan for 2013/14-2015/16 NHS Newcastle West CCG identified "Support to carers" as a specific project within their plan on a page, linking to national NHS policies. NHS Newcastle North and East CCG, also within their Locality Commissioning Plan for 2013/14-2015/16, identified Whole system transformational programme – older people with complex health and social care needs" as a change initiative with an outcome of "Increased awareness of carers' issues and strategies to better support carers in their caring role". These projects will be continued to be taken forward under the newly unified NHS Newcastle Gateshead CCG.

Figures from the Census 2011 show the enormity of unpaid care in Newcastle:

Table 1: Care in Newcastle	
Total population	279,100
Providing unpaid care	25,644
Providing 1-19 hours per week	15,177
Providing 20-49 hours per week	3,705
Providing 50+ hours per week	6,822

Source: Census 2011

Table 2: Number of people providing hours of unpaid care per week by age

	0-24 years old	25-49 years old	50-64 years old	65+ years old	Total
1-19 hours	1,656	5,777	5,611	2,073	15,177
20-49 hours	295	1,501	1,252	657	3,705
50+ hours	283	2,248	2,049	2,242	6,822
Total	2,234	9,526	8,912	4,972	25,644

Source: Census 2011

There is general acceptance that these statistics are not wholly accurate as many carers remain unidentified.

To identify and support young carers, the Newcastle Joint Commissioning Strategy for Young Carers was developed and launched in 2014. The Strategy will be implemented by staff from a range of statutory and voluntary and community sector (VCS) organisations and it will ensure that young carers are not disadvantaged by their caring role and responsibilities. It will also ensure there is early identification and intervention to prevent children and young people taking on inappropriate caring roles and that they have the best possible chance of fulfilling their potential.

The key principles of the Strategy are to:

- Safeguard children.
- Develop a whole family approach to needs-led assessments.
- Ensure young carers and families are seen as the experts in their own lives.
- Ensure young carers have access to the same education and career choices as their peers.
- Continually raise awareness of young carers.
- Provide safe, quality support to children who continue to be affected by any caring role within their family.

Newcastle Carers is the current main commissioned provider of dedicated services for adult carers. They are also the Newcastle network partner of Carers Trust and work to the Carers Hub which is a comprehensive and personalised model of carer support. Young carers are currently supported by the main commissioned provider, Newcastle Young Carers run by Baranardo's. There are a range of other organisations providing support for carers and families focused on particularly conditions, for example Newcastle Positive Response to Overcoming Problems of Substance misuse (PROPS) and North East Special Needs Network

1.4 Planning Group

To help plan and organise the conference, a planning group was established which decided on the purpose and outcomes of the event. Membership of the planning group included:

- North of England Commissioning Support
- NHS Newcastle Gateshead CCG, Engagement Leads

- NHS Newcastle Gateshead CCG, Lead Nurses
- Newcastle Carers Centre
- Newcastle City Council
- Barnardos
- Mental Health Concern
- Elders Council
- Quality of Life Partnership
- Carers

1.5 Attendees

One hundred and thirty two people attended the Caring about Carers Conference (for a full list of attendees, see Appendix 1). Attendees came from a range of sectors including health and social care commissioners, primary care, secondary care, social care, mental health, voluntary and community (VCS) organisations, schools and higher education as well as a number of patient representatives and carers.

Section 2 - Conference programme

2.1 Conference programme

The structure of the conference consisted of a range of speakers in the morning, including a theatre performance and film, and a range of workshops focused on different topics in the afternoon followed by a panel discussion. For a full programme of the event see Appendix 2.

The presentations and information from the conference can be viewed at the links below:

<http://www.newcastlegatesheadccg.nhs.uk/caring-about-carers-conference-developing-good-practice-across-newcastle/>

2.2 Keynote speakers

To open the conference, Dr Guy Pilkington, Chair of NHS Newcastle Gateshead CCG, introduced the focus and outcomes for the day and described the CCG's commitment to see practical actions identified and taken forward in contract specifications. There was acknowledgement of the issues faced by carers and that the system supporting carers is often under resourced.

2.2.1 Ewen Weir, Director of Wellbeing, Care and Learning, Newcastle City Council

Ewen was the keynote speaker and he provided a strategic perspective to thinking about carers. He reflected on his personal experience of caring, in particular, that he had found the care system difficult to navigate despite his knowledge of organisations and the system. The presentation also outlined statistics about the number of carers in Newcastle.

With the value of unpaid care across the country totalling approximately £119 billion (Valuing Carers, 2011, Carers UK and University of Leeds), the importance of informal care is clear – without unpaid carers the care system would be unable to cope with demand.

The key theme from the presentation was the breadth of issues that carers have to deal with and the range of challenges this brings, both for carers and for the system supporting carers. The challenges faced by carers, such as ill health, leaving work and financial difficulties, coupled with insufficient recognition and support from the health and care system, highlight the need for significant changes to be made.

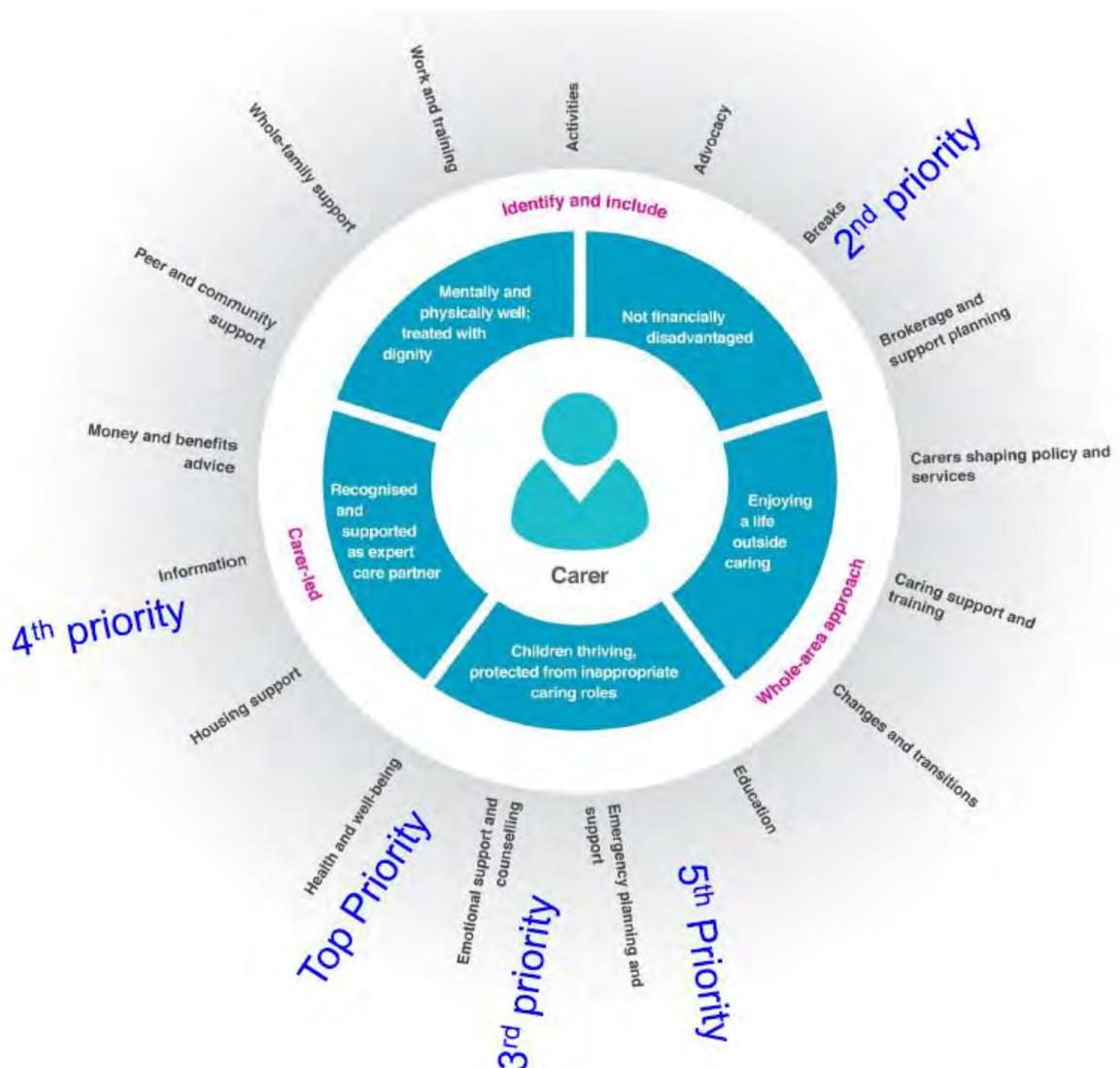
2.2.2 Fiona Richardson, Carers Lead Officer, Newcastle City Council

Fiona spoke alongside Ewen Weir and began by detailing the journey so far for carers' legislation and guidance to set the policy landscape for discussions. The presentation outlined the National Carers Strategy developments and the upcoming Care Act 2014.

The Carers Trust developed a 'hub' model to show what is important to carers (see image below). The 'hub' model shows the carer in the centre, surrounded by five principles from the National Carers Strategy with a further 17 aspects of the lives of carers around the outside. This was used in a consultation in Newcastle to ask carers what they think is working well and what could be improved in relation to the 17 aspects displayed on the 'hub' model.

From the consultation the top five key priorities for carers were identified:

1. Carers own health and wellbeing
2. Carers having a break
3. Emotional support and counselling for carers
4. Availability of information for carers
5. Emergency planning and support for carers and the person in need of care



2.3 Dr Raj Bethapudi, GP Carers Champion for the Royal College of GPs (RCGP), GP and Carers Lead for NHS Sunderland CCG

Dr Bethapudi, spoke of the role of general practice in identifying and supporting carers. In his GP Carers Champion role with RCGP, Dr Bethapudi aims to help primary care to support carers; to liaise with GPs to make support for carers more robust; and to link with other VCS organisations. The RCGP have already completed work to provide a carer's evidence summit which consulted with carers to find out what works well, what could be improved and what commissioners need to do to help carers.

RCGP have also created a range of e-learning resources for a variety of health professionals, social care professionals, VCS organisations and commissioners known as the Caring for Carers Hub which is also available for carers. The Hub provides information at a national and local level with the local CCG owning the site and populating the Hub with services and information. RCGP provide evidence to support the information.

As a GP, Dr Bethapudi also outlined the challenges faced by primary care staff in relation to the early identification of carers and meeting their needs. One of the key issues for primary care is the need for greater partnership working across sectors to ensure that when an individual accesses a service, carer issues are always considered. Another key issue is the time constraints and workloads of GPs which suggests that they cannot be responsible for carer issues alone. Good practice in carer identification and meeting carers' needs should be embedded into working practice to ensure sustainability. Many carers do not place the 'carer' label upon themselves and continue to only see themselves as a mother, father, son or daughter of the person they are caring for which makes it difficult to identify and support carers. Finally, another challenge for GPs, and other health and care professionals, is the issue of consent and cooperation.

The work of NHS Sunderland CCG in carers' improvement was explained to share good practice and outlined a scheme with an investment of £375,000. The carers' improvement scheme includes reviewing GP carer registers, many of which are 10-15 years old, and committing to update and improve their record which, in practice, means greater identification of carers. The scheme also includes the implementation of a Carer Lead in each GP practice who is able to access support workshops about carers' issues. For carers, the scheme provides more resources for carer health including health checks, flu jabs and depression screening.

The key theme from Dr Bethapudi was the need for better communication and partnership working across primary care, secondary care, VCS organisations and CCGs to improve care for carers.

2.4 Open Clasp Theatre Company

Open Clasp is an organisation that creates theatre performances based on the lived experiences of marginalised women and young women. They provided a performance entitled 'Living my life: an insight into a life caring for someone' which is an extract from 'Swags and Tails', a production looking at issues affecting older people and carers. The performance was set in a care home and the main focus of

the theatre performance was on May's story, a daughter of one of the residents, who previously cared for her mother at home.

May described her story where initially, after her father had died, her mother became forgetful and began to wander around the neighbourhood. As the situation worsened, May would often receive phone calls about her mother, for example, the police found her mother's front door open but no one was in the house. Her mother's health declined further and May became worried that her mother would come to harm or harm someone else because of her actions. May became her main carer, despite being one of seven children, but she also had to continue working which meant she could not be with her mother at all times. The family decided to have care workers come into her mother's house to provide support but this made the situation worse as her mother was confused and was sometimes unsure if they had been at all. The situation reached a crisis point for May who felt unable to cope and the only option was to place her mother into a care home.

After the performance, each table took part in an activity to chart the timeline of the events detailed in the performance and to discuss how the situation affected May, both as a daughter and carer, over the years. Below is a summary of the findings from the activity:

Event	Effect on May as a carer
Year 1: 5 years previously, May's father died, her mother became forgetful	<ul style="list-style-type: none"> • Feeling bereaved, fearful and anxious • Grieving her father's death but has uncertainty about her mother's health • Daunted at being the only daughter to help and at the extra responsibility • In a crisis, other family members help but life returns to normal and it's likely she will feel lonely
Year 2: Mother's condition deteriorates, May is her mother's main carer, lack of support from siblings	<ul style="list-style-type: none"> • Ability to work is impacted and the situation is likely to impact on May's physical and mental health • Feeling exhausted, overwhelmed, lonely and isolated • Her mother was the centre of her world so she is angry and feels guilty • Anxious because of her lack of knowledge about the situation
Year 3: Care workers are going into her mother's home which should give May peace of mind and extra support	<ul style="list-style-type: none"> • Feeling stressed, frustrated, guilty and anxious that she is the main contact for care services but also that she isn't caring for her mother • Feeling worried that the care workers aren't doing their job properly

Year 4: The care for May's mother is not working well and May reaches breaking point	<ul style="list-style-type: none"> • Very stressed and at risk of a carer breakdown • Depression, frustration and anger at the whole situation
Year 5: The family decide that May's mother should go into a care home, May takes a holiday	<ul style="list-style-type: none"> • Extreme guilt and loss of her mother's identity • Angry that the care home is not like 'home' • Concerned and worried about the quality of care

Following the discussions, Open Clasp led an activity with all delegates to identify services or support that would allow a carer in crisis to be fully supported. The activity was to create a human bridge with a carer in crisis at one side and a fully supported carer at the other side. The delegates identified methods of support and decided an appropriate order for those actions, and each person represented part of the bridge. The actions identified included:

1. Provide information resources
2. Someone to be a lead in the care to access support and be in charge of the information, for example using a Common Assessment Framework (CAF)
3. Carers need to speak up and ask for support of others, particularly family members, at the very beginning
4. Carers should also be more proactive and take responsibility to access services
5. Proactive commissioning by commissioners to put services in place to support carers
6. Good communication systems to allow carers to navigate the system
7. Ensure services are joined up as the services do exist but they are fragmented
8. Providing breaks for carers so they can have a life of their own
9. Once empowered through previous steps, carers should have the ability to speak to their family about extra support if this was not possible at first

2.5 Paul Brownlee, Service Manager, Young Peoples Services, Newcastle City Council

Paul highlighted the challenges faced by young carers and the need for services and support.

Three key elements were highlighted in relation to young carers. The first is the need for services to work together, across organisational boundaries, to help young carers and to develop new ways of working to achieve these goals. Single agencies should not work in silo and information should be shared across teams, departments and organisations.

The second key element is the need to put young carers first. Young carers have a need and a right to have an education, be presented with opportunities and have employment prospects as well as have a life of their own and a childhood. Young

carers must be protected from inappropriate caring roles and provided with the same opportunities as other young people.

The final key element is the need for focused, family-based work which achieves results for the whole family unit. This would allow the identification of young carers and provide support to the whole family, whilst inevitably protecting young people from the inappropriate carer role.

The presentation outlined the Newcastle Joint Commissioning Strategy for Young Carers, launched in 2014 which aims to identify and support young carers.

Generally, an underlying element is the need to understand why young people are caring. In most cases, there is an adult in need due to physical or mental health problems or issues such as substance misuse. To ensure young people are removed from a caring role, these issues need to be addressed in their own right.

A film was shown of Amelia's story, a young carer looking after a family member with a personality disorder. Amelia had been caring for a family member for a number of years and was identified through her school when she began to fall behind with work. Amelia's school provided support and were very understanding of her situation, however, away from school Amelia's social life began to suffer. Amelia could not spend time with her friends because of her caring commitments. Amelia was introduced to Barnardo's Young Carers, Newcastle, and they provided a whole range of support so Amelia could lead her own life beyond her caring responsibilities.

Section 3 - Workshop findings

3.1 Workshop findings

There were 10 workshops focused around six themes:

- Issues and needs of young carers
- Issues and needs of adult carers
- Carers of older people
- Carers of people with mental health concerns
- Carers and primary care health services
- Carers' issues

In each group, three main questions were asked to gain an understanding of each theme:

1. What is good about carers' experiences within your own organisation?
2. What are the three main change proposals from the conference you will take back into your organisation?
3. What are the three key considerations that health and care need to build into future strategy and services for carers in order to best address the issues raised within conference discussions?

Each table discussion was led by a facilitator to guide discussions and a note taker to capture the information. Each facilitator had a range of tasks and sub-questions to enable participants to answer each question and to aid discussion. Discussions were carried out as a whole group and in pairs with feedback to the wider group supporting all participants to contribute. The facilitators each took a difficult approach to the discussion so the information obtained is not in a standard format.

This section provides a summary of the findings within each workshop theme.

3.2 Issues and needs of young carers

The issues and needs of young carers were discussed by one table with representatives from organisations and groups including:

- Newcastle upon Tyne Hospitals NHS Foundation Trust (NUTH)
- NHS Newcastle Gateshead CCG
- Young Adult Kidney Coordinator
- Cruddas Park Surgery, Newcastle
- Public Health School Nurse
- Newcastle Young Carers
- Streetwise
- Roots and Wings
- Northumbria University
- Tyneview School

3.2.1 What is good about carers' experiences within your own organisation?

Although not all organisations represented in the discussion had day-to-day involvement with carers, there were clear themes that emerged from the experience of those that do work more closely with young carers.

The main positive experience was having the skills to be able to listen to the needs of young carers and taking time to build trust with the individual, thus giving them the confidence to confide in professionals offering support. Respecting young carers is important, ensuring their knowledge of their own situation is used and valued.



The identification of young carers should be carried out in a sensitive and constructive way. Young people do not always present as carers. They can present with other issues such as self-harming so the situation can be hidden. There needs to be an appreciation of the fear and anxiety young people may face of what might happen if they share what is happening at home – such as social services getting involved, or being removed from home.

We therefore need to be more pro-active in identifying young carers, Professionals should work to identify young carers, whether at home or school, and should be able to provide the correct support at the correct time, tailored to the individual, whilst also recognising that young people are resilient and capable of making their own decisions.

3.2.2 What are the three main change proposals from the conference you will take back into your organisation?

The discussion focused on the issues that require change rather than proposals to take back to participants' specific organisations.

There was a discussion on the importance of education establishments in identifying and supporting young carers, particularly as the universal, non-stigmatised point of contact for young people. Teachers are often able to identify students that are struggling with aspects of school life, however, the school often focus on the safeguarding route to support young people. It was felt more responsibility could be taken to refer to relevant support agencies that can provide specific, targeted support rather than relying solely on safeguarding processes.

It was also identified that further support within school settings could come via school nurses and school health services, where it should become commonplace to ask additional questions about whether the child or young person is caring for anyone else. For example this could be during Hello/Goodbye sessions designed to

allow parents and carers to say goodbye to their Health Visitor and hello to their new School Nurse.

Raising awareness of young carers, their needs and issues, within schools was also an important aspect of discussion whereby peer mentors, an individual with a lived experience, could provide information and support to young people as well as helping to identify young carers.

“We need to remember it’s not expecting young people to come to you. You have to go to them whether that is at school or at home.”

Away from the school setting, there was recognition of the need to help young carers at university where no allowances or support is currently being given to young people in a caring role.

Aside from education establishments, there was discussion around what exactly is an appropriate caring role for a young person. We need to work in partnership with young carers and their families to assess, discuss and agree what is meant by ‘appropriate’ caring roles, and further agree what support package can be brought in around the family to reduce caring. There was general agreement that this can require in-depth and lengthy discussions with young carers and families, followed by contacting external agencies to negotiate appropriate support for the cared for person.

A discussion was also held on the need for better communication with young people and young carers. The main change proposal was to consider the language used when communicating with young carers. Terms like ‘assessment’ often instil fear with the implication that, for example, social services means being taken into care. The basic need to communicate with young people in language they understand is essential to ensure that young carers feel confident and comfortable with stepping forward to identify themselves as in need of additional support.

In addition, there is a need to reduce the stigma attached to carers. Young carers often do not identify themselves as a ‘carer’ and see it as ‘just something they do’ which creates barriers to young people accessing services.

Another change proposal identified was to ensure services work harder to build trust with young carers to enable them to be more open and honest with professionals, particularly to discuss their needs as carers. In many cases, young carers fail to tell professionals everything, partly through fear and lack of trust, which prevents them from benefiting from the full support they need. Alongside better communication in promoting trust, young people should also be given more time to speak with professionals and there is need to respect the carer’s knowledge of their own situation.

“No-one can explain their circumstances better than the carer. We need to respect the knowledge young carers have of their own situation.”

Further discussion was given to the need for GPs and GP practices to have more insight into the issues and needs of young carers, including more mechanisms to identify young carers and ways to support them. The recognition of this also contributed to a discussion around the importance of early identification to prevent

situations escalating to a crisis point and, therefore, reducing the negative impact on young people.

Other discussions included the issues surrounding patient confidentiality with regards to information sharing across organisations, and the need to take a family approach to helping young carers to ensure the whole family have the correct support in place.

3.2.3 What are the three key considerations that health and care need to build into future strategy and services for carers in order to best address the issues raised within conference discussions?

The workshop discussions outlined three key considerations for health and care to consider:

- Developing a system and process to make ‘every contact count’
- Involving young carers in commissioning decisions and services based on a young person friendly model using their language
- Developing a Newcastle information hub

“There is a lack of general awareness of the provision that is available.”

These considerations stemmed from the discussions for question two and were seen as solutions to some of the issues faced in the identification and support of young carers. As well as the three main key considerations, a range of other change proposals were discussed:

- To have advocacy, mentors or link workers to help young people navigate the care system
- To have peer mentor education in schools and to have a whole school system approach
- Ensure there is continuity of services and staff wherever possible, particularly in relation to transition to adult services
- Consult with young people about the language used
- A promotional campaign to promote the identification of carers, for example posters in schools and GP waiting areas with suggested questions including ‘Do you do your family shopping? Do you go to the chemist for a relative?’

3.3 Issues and needs of adult carers

The issues and needs of adult carers were discussed by two tables with representatives from organisations and groups including:

- Carers
- Newcastle Community Stroke Services, NUTH
- Adult Social Care Services, Newcastle City Council
- Respite Day Services, Newcastle City Council
- Northeast Special Needs Network
- Newcastle Carers
- Stroke Association

- West End Befrienders
- Dementia Care

3.3.1 What is good about carers' experiences within your own organisation?

A range of good adult carers' experiences were discussed including general examples of good practice and support available from specific organisations.

Adult Social Care Services, Newcastle City Council, identified that they provide practical support for carers and aim to build trust with those they contact. They recognise that there can be a stigma attached to social services which instils fear of having the service involved in their situation and they try to remove those barriers and provide the carer with the support they need.

“We try to build up trust because they [the carer] get scared if they're told a social worker is going to see them.”

One of the main positive experiences for carers' outlined was the range of services which provided access to information for carers. Adult Social Care Services, Newcastle Community Stroke Service, Stroke Association, Newcastle Carers and Northeast Special Needs Network all outlined that their services are able to provide and access information on behalf of carers. The care system can be difficult to navigate and these services offer to take a carers issue and try to resolve it for them to reduce their stress and enable the carer to focus on their caring role.

“We work with whatever the problem is. We don't ever pass people from pillar to post, we would take on the issue instead. Even if we don't know the answer, we'll look into it for them instead of leaving them [the carer] to sort it out.”

Newcastle Community Stroke Services also discussed the availability of their Caring for Carers course and follow-on support group which provide training and ongoing support for carers. Despite these services providing a positive experience for carers, it was recognised that the uptake can be low because of carers' time constraints.

Northeast Special Needs Network supports the inclusion and recognition of parent carers. As well as providing support around access to information, they are a non-judgemental service, supporting parent carers to identify what their disabled child/young person needs and working with the whole family to ensure that support is in place.

Stroke Association provides long term support to carers in their own home. In most cases, the support they provide is for those caring for a family member or friend who has suffered a stroke and, consequently, suddenly finds themselves in a caring role. As well as providing advice and information, they provide continuity of care, recognising the carer's needs are separate to the person they are caring for by providing emotional support and the privacy to talk openly.

“We realise carers' time is precious so we go to their house so they can carry on with whatever they need to do rather than coming to see us and having to rush back.”

Respite Day Services, Newcastle City Council, provide services for the person carers are caring for enabling carers to have a break. The day service works with life-long carers who often have multiple caring roles. Despite providing breaks for carers', the service would like to improve the contact with carers to be able to better support them as well as the person they are caring for.

Other examples of good practice were also discussed with the main positive experience relating to good communication. It is essential to ask the correct questions to help identify a carer, for example, rather than asking 'Who is your carer?' ask more open questions such as 'Who helps you every day?' or 'Who does your shopping?'

Enabling carers to have the time they need to talk to services ensures they receive the support they need and that they feel they have been listened to. This is essential in providing a good experience.



3.3.2 What are the three main change proposals from the conference you will take back into your organisation?

Some services identified changes that they could take back to their organisations whilst there was also a wider discussion about more general changes that need to take place.

Adult social care services identified that they could ensure carers are asked if they would like to be referred to Newcastle Carers rather than a worker providing a leaflet and leaving the onus on the carer to contact the service. They also suggested that Newcastle City Council could carry out an audit to detail the number of registered carers and the number of assessments carried out which could be used to set targets in relation to the identification of carers.

Respite day services identified changes they could make to improve the experience for carers by making the contact with workers less formal. The service is already in

the process of making improvements by using DVDs to show the carer what the person they are caring for has been doing while in the day service. This allows a more informal dialogue with the carer to build a relationship and moves away from the situation whereby carers are only contacted when paperwork needs to be completed.

Respite day services also identified that more signposting into their service would be a positive step for carers and the person they are caring for. The service would also like to signpost to other organisations that could provide advice, information and support to carers but need a resource which enables staff to know what is currently available in Newcastle.

“Services have been cut so much everywhere and it’s knowing where to go and who does what now. My staff often phone an organisation but they don’t deliver a particular service anymore but we didn’t know.”

More generally, Northeast Special Needs Network were very keen to see the co-location of services to benefit the carer and the person they are caring for whilst the Stroke Association identified that more support groups for stroke survivors would benefit the person they are caring for whilst also providing respite for the carer.

One of the main discussions centred on the need to share information through a greater link between primary care, social care and VCS organisations. Adult social care services identified the need to have a primary care link during carer’s assessments to allow carers and their needs to be recognised and better supported. Other organisations also identified that the carer’s assessment should not be a ‘one off’ assessment but should be built upon to gather information on an ongoing basis which can be used to better support the carer and the person they are caring for into the future.

The importance of a joined system was also discussed in terms of preventing carers from being repeatedly asked for the same information by different agencies. Better information sharing between healthcare, social care and VCS organisations would ensure a carer is supported more effectively and would promote wider partnership working.

Another key discussion was the need for better and greater availability of information. A variety of information was needed in a variety of formats including different languages and made available via different platforms. This information should be made available for professionals and carers and should include positive stories and case studies which would provide carers with the confidence to access services. This kind of information would also work towards reducing stigma of carers and promote the need to access support services.

It was also suggested there was a need for local authority carer’s assessments to change to be more person-centred. The assessment should be done in partnership with carers rather than ‘done to them’ which would ease the fear and stigma associated with the assessments and should focus less on ‘box-ticking’.

3.3.3 What are the three key considerations that health and care need to build into future strategy and services for carers in order to best address the issues raised within conference discussions?

Three key areas were identified for health and care to consider and, in addition, a wide range of further considerations were also discussed:

- There is a need for better information sharing across organisations including primary care, secondary care, social services and VCS organisations. This would deliver continuity of support as well as providing a better service for the carer with more targeted and appropriate support. It was seen as vital to have a carer's health records as part of the process of supporting the carer and a GP could provide that link.

“A GP is important in the needs and care of a person but they don't get given the information from the social workers. There needs to be an understanding of their medical history, even if the GP isn't contributing, the information needs to be in the process.”

- There is a need for better information provision for professionals in all sectors as well as for carers. This includes a directory of available services, kept up to date, allowing professionals to refer or signpost to relevant organisations for support. There was also a need for a central information point which included information about complex health conditions, written honestly and in a way the carer can understand.
- There is a need for more transparency in funding decisions. Initially, there is a need to define the budgets to show where the funding for various services is from and, in relation to that information, where the criteria for accessing services begins and ends. This would allow discussions around merged funding to take place which could allow for greater service provision for carers.

Other considerations for health and care to build into future strategy and services for carers included:

- There is a need to ensure carers are valued and respected for the role they play in the care system. This includes considering the overall wellbeing of the carer and what can be provided to improve that.
- Ensure parent carers are considered as many continue to see themselves as 'just the mother/father'.
- Greater partnership working across organisational boundaries to provide a better service to carers.
- A need to think about the language and terminology used in these formal processes which can often be off-putting to a carer. This is also true when considering supporting carers to know what questions they need to ask and how to respond to formal processes.
- Especially in large organisations, there is a need for training and awareness raising amongst staff which should be communicated continuously, for example, through newsletters.
- Consider the way funding is made available to organisations. There is often start-up money available for a service but when the funding ends it is no

longer sustainable which creates a fragmented and confusing landscape for signposting and referrals.

- Ensure the VCS is considered in commissioning and not taken for granted. Many VCS organisations find funding difficult and are constantly taking on more roles and responsibilities as other services are cut.
- Consider the co-location of services to provide a better experience for those accessing services.
- Specific services for carers should be commissioned and identifying carers should be included in all letters/forms/contracts/outputs for all tenders and commissioning processes.
- There should be a vision for carers which is not restricted by resources, is carer led and focuses on what can be done.
- The need for funding or resources for a carer's voice that can provide multi-agency networks, support funding bids and provide practical support.
- The use of plain English, avoiding jargon is necessary when supporting carers.
- Recognise cultural barriers for some communities when thinking of themselves as a carer or accessing services, as well as ensuring the use of interpreters when it is necessary to do so.
- Consider carers being more involved in delivering talks and training to professionals.

3.4 Carers of older people

The issues and needs of carers of older people were discussed by one table with representatives from organisations and groups including:

- Carers
- Northumberland, Tyne and Wear NHS Foundation Trust (NTW)
- Community Response and Rehabilitation Team, NUTH
- The Grange Day Centre
- Newcastle Councillor
- Newcastle City Council
- Your Homes Newcastle
- Byker Lodge Care Home
- Search Project
- Quality of Life Partnership
- Elders Council of Newcastle
- West End Befrienders

3.4.1 What is good about carers' experiences within your own organisation?

A range of good experiences in relation to carers of older people were discussed including general examples of good practice and specific support available from organisations.

Search Project, a community based resource centre for older people and their carers, identified their singing project as a huge success in providing a positive experience for the carer and the person they are caring for. It provides enjoyment

and pride for people with dementia allowing them to take part in an activity they can contribute to.

Byker Lodge Care Home identified that taking a husband and wife out together provided a positive experience for the person being cared for and the carer and provided them with a break away from the care home.

Elders Council of Newcastle was keen to share the importance of caring for the carer as well as the person they are caring for, including the importance of small changes to improve a person's quality of life and wellbeing.

“Small things for the carer such as adding small touches to a bathroom or putting candles in.”

The discussions also identified the need to develop a relationship with the carer to ensure they are receiving the support they need which, to some extent, should be able to anticipate carers' needs to prevent a crisis situation from developing. This kind of ongoing relationship promotes positive communication enabling the carer to be open and honest.

“There was a husband and wife both in care but the husband's health deteriorated. To help the wife cope, anticipating the need for short breaks would have been helpful instead of waiting for a crisis point.”



In addition, a close relationship with the carer would also mean that professionals are able to identify opportunities to intervene, when necessary, and are able to signpost to further support. Being proactive in the approach to carers of older people provides a positive experience.

Being able to plan ahead for the carer and the person they are caring for was also seen as essential in providing a good experience. This means planning for a crisis situation so there is a clear route to follow when things do go wrong. Not only can this help to formalise the carer role, which is helpful to the carer and the person they are caring for, it also means the carer can be more involved in the decision-making rather than trying to make decisions during a stressful situation. Being able to make those decision in advance can also help a carer when they are no longer able to provide care as they can still be involved in care planning.

More generally, positive experiences for carers of older people centred on the need to listen to carers and offer support as well as providing opportunities for carers to share experiences and reach out to others in similar situations.

3.4.2 What are the three main change proposals from the conference you will take back into your organisation?

The discussion focused on the issues that require change rather than proposals to take back to participants' specific organisations.

There is a need to change the way information is made available, specifically to carers, to help people access advice when they require it. Carers struggle to find information about basic issues and they are often unaware of what services exist. This means that carers are often at breaking point before accessing support which ultimately costs more to services long term. If professionals have the information to provide to carers and carers are able to access information easily, this system change would have multiple benefits. There was also recognition that the carer is often supported by their friends and family and information should be easily accessible to them.

Following from the need to share information, there was a discussion about the need for a website which would have all of the information in one place, however, it was recognised that this would be valued by some but others, such as older carers, may not have access to this type of resource. There should be options for accessing information, including the opportunity for carers to speak to someone in person.

Another change proposal, linked to crisis care planning, is a care system with support triggers. In many situations the carer or the person they are caring for will not recognise or admit to professionals that they can no longer manage the situation. In these circumstances, a system of support triggers whereby extra support is accessed easily and quickly could prevent crisis situations, reducing the pressure on services long term and reducing the negative impact on the carer and person they are caring for.

“The person who is being cared for will not admit it and will believe that their carer is managing for example their daughter may have a full time job and children but they will think they are managing. They'll only want to call on their daughter for care.”

It was also suggested that there should be two carer champion roles. The first would focus on the need to have carer champions, each who have experience of caring, based at a local hub to reach out to communities. Their role would be to raise awareness of carers, help to identify carers and provide peer support. The role should fit with the wider care system so that champions can refer into more specialist services for carers requiring further support. To start with, simple activities such as coffee mornings or drop-in events could be held and, as the services become established, the need for more carer support groups could also be fulfilled by this role.

The second carer champion role would be based within organisations to raise awareness amongst staff members and stressing the importance of identifying carers. Carer champions within organisations could lead on building staff knowledge of carers, carers' issues, good practice and disseminating it throughout their organisation or team.

Frontline staff from a variety of agencies identified that there are key points at which they would become aware that a carer is supporting an individual and that, as professionals, they could do more to identify carers and provide support. For example, an attendance allowance application would suggest that a person has a carer and the officer assisting with application could do more to try to identify the carer and signpost to further support.

Investment in VCS organisations was seen as a key change proposal which could ease demand on other services while providing a more holistic approach to caring for the carer.

Another change proposal surrounded the assessments and referrals of carers and the need to reduce delays in the process. Often bureaucratic, delays can cause hardship and can lead to crisis situations escalating due to lack of support. Beyond the initial assessment, the need to continue contact with the carer should also be implemented to ensure the support they receive is appropriate and, if not, the support can be changed or improved.

With much of the discussion focused on preventative measures to put services in place to reduce crisis situations, there was also a change proposal centred on the need to improve emergency care for carers and to those they are caring for. When things do go wrong, there should be services available that carers are able to contact.

3.4.3 What are the three key considerations that health and care need to build into future strategy and services for carers in order to best address the issues raised within conference discussions?

More than three key considerations were discussed for health and care to build into future strategy and services, they included:

- Commissioners should include carer issues in contracts with suppliers to require organisations to work together and to ensure carer issues are always considered within provided services. For example, this could include the need for organisations to work to identify carers within their service delivery, particularly for those that are likely to come into contact with or support families or individuals where caring roles are commonplace.
- Linked to the need for a collaborative approach is the requirement for information to be available and easily shared across organisations. This related to the need for up to date information about carers' issues and the availability of services as well as the need to share information with relevant support services about individual cases to better support the carer. Relevant information should be available for professionals to provide to carers and equally should be available for carers to access themselves.
- A campaign to raise awareness of carers and carers' issues was identified as an important factor. There is a need to raise awareness amongst communities through advertising following the positive example of 'Dementia friends'. The campaign should aim to reduce stigma and encourage more people to come forward to receive the support they need.
- There is a need to provide sufficient time for carers to talk to professionals. The initial discussions about positive carers' experiences identified a need to build a close relationship with carers and provide opportunities for good

communication. Carers often need more time to build trust with a professional to be able to admit that they need help with their situation.

- There is a need for better crisis care planning was an important consideration to allow carers to step away from their role when they need to. Advance care planning for crisis situations would reduce the reliance on crisis services and would have a more positive impact on the carer and the person they are caring for.

3.5 Carers of people with mental health concerns

The issues and needs of carers of people with mental concerns were discussed by one table with representatives from organisations and groups including:

- Adults Wellbeing and Health, Durham County Council
- Older Persons Community Mental Health Team, Newcastle City Council
- Mental Health Social Work Service, Newcastle City Council
- Community Psychiatric Nursing Team, NTW
- North of England Commissioning Support
- NHS Durham CCG
- Newcastle Young Carers
- Barnardo's
- VOLSAG
- Mental Health Concern
- Mental Health Matters
- Moving Forward South Tyneside, Mental Health Concern
- Newcastle Carers
- Advocacy Centre North
- Northern Initiative on Women and Eating (NIWE)
- Health and Race Equality Forum (HAREF)
- Newcastle Talking Therapies

3.5.1 What is good about carers' experiences within your own organisation?

Newcastle Carers provides a good experience for carers by offering services tailored to the carer as an individual, offering respect and emotional support. Newcastle Carers is also carer-led.

Advocacy Centre North offer a close working relationship with carers to identify potential conflicts between the person being cared for and the carer. Wherever possible, the aim is to work together with the person being cared for and the carer to support them to work as a team, enabling the carer to be an advocate for the person they are caring for. For example, where the carer suffers mental health problems, they need to be able to access support for themselves which will then enable the individual to support the person they are caring for. In some circumstances a specialist advocate might be offered if the carer feels unable to provide the advocate role for the person in need of care.



Mental Health Social Work Service, Newcastle City Council, identified their positive experience for carers as their duty to offer carer's assessments. This ensures that carer involvement has been considered and their needs have been addressed, as well as putting carer plans in place and signposting individuals for further support. They also provide direct payments for respite care which is focused on the need for the carer to have a break and direct payments to sustain the carer role.

Older Persons Community Mental Health Team, Newcastle City Council, provide a good experience by identifying carers and helping them to access services they need.

NIWE provide a listening service to help support carers to understand the issues and

concerns they may have in their caring role. The aim is to build carers' confidence so they are fully equipped to deal with their caring role.

Newcastle Young Carers identified their positive carers' experience to be their provision of a whole family approach to supporting carers. They work hard to overcome fear of statutory services in families and work to reduce the care role and the impact it has on the family. They provide close links with disability services and provide practical support as well as signposting to other services that can further support the family. They also identified that they provide a range of awareness training and family support. However, it was identified that they find mental health and primary care referrals difficult.

HAREF work to highlight needs across diverse ethnic minorities in Newcastle with the aim of improving access to services and raising awareness of relevant issues. They produce information for men from black, minority and ethnic communities that are identified as carers.

Mental Health Concern offer a positive, proactive approach ensuring carers are always considered in all aspects of their work. Having improved their knowledge of carers' issues recently, they have reviewed how they communicate with carers and staff are now trained to know more about how to deal with carers' issues.

Newcastle Talking Therapies outlined their positive experience for carers' as their focus on the individual. They provide short term intervention to link with long term conditions.

Mental Health Matters provide a positive experience by aiming to create space for carers to feel able to talk. Their staff always ask about carers when speaking with service users ensuring support is in place for the individual in need of care and the carer. They have also developed close links with mental health and young carers.

Moving Forward, Mental Health Concern provide a positive experience by listening to carers' needs, ensuring there is support in place and helping to facilitate activities that can help individuals.

VOLSAG identified that they try to provide a voice for carers in service changes, for example, the recent mental health consultation.

3.5.2 What are the three main change proposals from the conference you will take back into your organisation?

The discussion initially centred on the current gaps in service provision then moved to focus on change proposals within organisations.

One of the main gaps identified was the lack of clarity and collaborative working between teams and organisations. There is a fragmentation between statutory services and VCS organisations and then within statutory services responsibilities are often passed between teams. For example, there are a whole range of organisations that support young carers in Newcastle but being able to facilitate organisations coming together is difficult.

In addition, there is currently a gap created between statutory services and VCS organisations as social workers are seen as reluctant to refer service users to other organisations. Links between such professionals are created through networking events rather than facilitated by specific referral pathways.

It was identified that there is seen to be a gap in information provision for teams within Newcastle City Council about services and support that is currently available in the area. However, most of the information exists but is out of date or is not accessible to all teams. Consequently, this often means there is a service in place but it is not being accessed.

“I was recently asked by the Council to give all of the organisation's details for a new database required by the Care Act. My action was not to do this, instead I asked how this new directory was going to link with the others and why aren't we using what we already have and creating a strategic, joint, sustainable approach.”

Finally, the discussion highlighted a gap in provision of mental health services for young people, particularly those under 16.

Organisations then identified change proposals or actions to take back to their organisations:

- North of England Commissioning Support
 1. To explore a market scoping exercise to look at provision across the whole pathway, analyse the findings and publish the report.

- VOLSAG
 1. Ensure that a carers' viewpoint or input is required, VOLSAG link with VCS carer organisations to gain that insight and knowledge.

2. Continue to focus on the need for a strategic, joint and sustainable approach to information resources that currently exist rather than creating new resources and directories.
- Older Persons Community Mental Health Team, Newcastle City Council
 1. To support the need for more scoping, as outlined by North of England Commissioning Support.
 - Newcastle Young Carers
 1. Increase provision for young carers.
 2. Support the steering group, working closely with the CCG, Local Authority and mental health services to look at what support is needed to help identify young carers.
 3. Support young people to understand young carers' issues.
 4. Build links with mental health teams to increase identification and to support our work with young carers.
 5. Look into information sharing and what information is available.
 - NHS Durham CCG
 1. Explore the Carers Hub
 - Mental Health Concern
 1. Explore the five priorities from the carer's consultation.
 2. Provide more direct and targeted information.
 3. Formalise the emotional support service provided to families when their loved one moved into a Dementia Care Service.
 4. Staff training to better understand the needs and dynamics of family relationships to build support for the carer.
 5. To improve family carer engagement in assessments and care planning processes.
 6. Aim to improve our consent to share information systems so communication can be clearer across organisations.
 - Community Psychiatric Nursing Team, NTW
 1. Ensure nurses know the Carers Hub exists and the website is there to be used by professionals.
 2. Promote communication with GPs to identify whether a carer is involved in a person's care.
 3. Ensure young carers are being supported.
 4. Work in partnership with social care services.
 - Mental Health Matters
 1. Take back information gathered from the Carers Conference.
 2. Develop channels for information.
 - NIWE
 1. Raise the profile of carers with mental health problems, including eating disorders.
 2. Provide information sessions and partnership work to enable carers to share experiences and gain information about what to do in a crisis.

3. Identify the main issues amongst carers NIWE work with, whether those caring for someone with an eating disorder or carers who have an eating disorder.
- Newcastle Carers
 1. Look closely at specific organisations to identify who provides carers services and what they do.
 2. Create referral pathways with other organisations.
 3. Promote Newcastle Carers to a wider audience.
 - Mental Health Social Work Service, Newcastle City Council
 1. Implement actions relating to our duties under the Care Act.
 2. More assertively address the needs of young carers in line with YCN pilot with physical disorders.
 3. Challenge GPs and primary care to identify more carers.
 4. Provide out of hours services in the future.
 - HAREF
 1. Work more closely with Carers Lead to get information about opportunities for black, minority and ethnic communities to be involved in discussion about service development.
 - Advocacy Centre North
 1. Understand and be aware of the new Care Act and ensure our role is clear.
 2. Continuing strong links with Carers Centre for mental health carers and identifying carers' needs.
 3. Strengthening the role of advocacy in the Mental Health Act, a new code of practice, to provide support to the relative and include them in assessments.
 4. Resources relating to Carers Hub.
 - Newcastle Talking Therapies
 1. Review Newcastle Talking Therapies' assessment forms to include questions about carer involvement.
 2. Review our database to ensure it is up to date and ensure people know what services are available.
 3. Explore subscription to Carers Hub.
 4. Explore how organisations can share information about available services.

3.5.3 What are the three key considerations that health and care need to build into future strategy and services for carers in order to best address the issues raised within conference discussions?

Three key areas were identified for health and care to consider and, in addition, some further considerations were also discussed:

- There is a need for greater clarity of roles and responsibilities of statutory services and VCS organisations, as well as amongst the varying teams within statutory services. There should be a way to standardise information

governance and funding to create clarity allowing organisations to work collaboratively.

- There should be accountability for information provision for the sector. Current and updated information about carers' issues and service available should be published regularly. More awareness of available services would allow overstretched teams to refer to appropriate support services and reduce the pressure within departments and organisations.
- Consideration should also be given to a public information campaign to reduce the stigma of being a carer allowing more people to benefit from the correct support. For this to be successful, the terminology used to communicate to the public should be selected carefully, it should be accessible and carers should be involved in the design.

“There is, in fact, another side to this, a reluctance, a stigma, about identifying myself as a carer and what this means for my relationship with the cared for person who is usually a loved one. What do they think of me being described as their carer? And underneath it all, there is a guilt that I cannot simply meet my mother's/wife's/child's needs. So a cultural shift is needed to make it more acceptable to see myself as a carer.”

Further considerations for health and care to build into future strategy included:

- Sufficient resources should be allocated to identification of carers and preventive support to allow carers to access support as early as possible. This would enable people to be supported before reaching a crisis point.
- Commissioning for Quality and Innovation (CQUIN) should be built into contracts to enable commissioners to reward excellence and to encourage innovation within the sector.

3.6 Carers and primary care health services

The issues and needs of carers and primary care health services were discussed by two tables with representatives from organisations and groups including:

- Patient representative, Denton Turret Medical Centre, Newcastle
- NHS Newcastle Gateshead CCG
- Teams Medical Practice, Gateshead
- Heaton Road Surgery, Newcastle
- Dilston Medical Centre, Newcastle
- Denton Turret Medical Centre, Newcastle
- Thornfield Medical Group, Newcastle
- Parkway Medical Centre, Newcastle
- Newcastle Young Carers
- Baranardo's
- PROPS

3.6.1 What is good about carers' experiences within your own organisation?

Some of the workshop participants acknowledged that within primary care it was difficult to identify carers, particularly young carers, but that GP practices are still working on ways to provide good experiences.



Newcastle Young Carers provides a good experience for carers by working with the whole family from the beginning of the process, whether this was from a school referral, GP or social services. Young carers are usually in a caring role because of an adult with needs and they work to address those needs to allow the young person to be removed from the caring role.

Teams Medical Practice, Gateshead, now follow a specific protocol for dealing with carers which means they provide a consistent approach across all healthcare professionals within the practice. The practice also has a Carers Champion, as most practices in Gateshead, and they work with and learn from Gateshead Carers Centre which allows a very simple referral process to be in place for carers to receive further support.

Thornfield Medical Group, Newcastle, identified that they are now providing a more positive experience as Newcastle Carers is located close to their practice making it easier to work together and promote their services to carers.

Dilston Medical Centre, Newcastle, work well when families attend appointments and do provide information about support services however, they identified that a cultural barrier exists within their practice population to support carers.

“We feel we don't know what services are out there for people who don't speak English. Our population has 35 different languages. It is in some cultures that they care for people. We work really well with the families when they come in for appointments and a lot of the time we give them information but they don't want to access the services. Translation can sometimes be difficult too as the word carer and depression doesn't exist in some languages.”

Denton Turret Medical Centre, Newcastle, have carried out a lot of work and identified their positive experience for carers as bringing carers as a recognised stakeholder group.

“We are going to start a carers group and we will be there to help signpost patients onto different organisations.” Patient representative

Heaton Road Surgery, Newcastle, holds regular meetings with discussion topics often focused on carers and carers' issues. This allows more information to be circulated, raises awareness and provides a platform for healthcare professionals to identify carers. Despite their positive experience, they recognise they have more work to do to improve carer identification and support.

Generally, it was felt that positive experiences should centre on a whole family approach to supporting carers which is consistent. Within a primary care setting, a Carers Champion can be a positive step but the role needs someone to drive the agenda within the practice who is also able to provide information and communicate with other staff within the practice.

In addition, some general issues were also identified by both workshop groups including the difficulty in referring into services when a person has an alcohol problem and the need for more resources for GP practices so they can focus on carer issues.

One workshop group found it difficult to provide good experiences within a primary care setting. They were able to identify issues relating to carers and primary care health services including the difficulty in identifying carers, the need for professionals to have more compassion with carers, the need for improved communication between organisations and the stigma attached to stepping forward to receive support as a carer.

3.6.2 What are the three main change proposals from the conference you will take back into your organisation?

The workshops identified a need for a carer definition that can be applied to all organisations to improve knowledge of carers and their issues. This could be done by all organisations involved in identifying carers or providing support. However, it was also noted that definitions do already exist, including a definition provided by RCGP.

An identified gap was the lack information about carers' issues and services that are available for carers. There is a need for a Carers Hub to provide the information in one place that can be used by all organisations but would provide a simple solution for GPs. This information should also clearly include any access criteria for the various services.

There was also a need for a Carers Lead to be identified within each GP practice to take the carers agenda forward and provide support to staff members within their practice. One workshop group also suggested the need for a Carer Champion amongst a cluster of GP practices that could also support the work of GPs and provide a way to share information and good practice. The cluster champion would not have to be a GP; it could be a peer support role, information management or a way to provide links with VCS organisations.

Specifically for primary care settings, the need to link with social services more closely was identified, to enable shared information and so carers can be better supported in all aspects of their health and wellbeing. The need to link with secondary care was also identified.

One GP practice expressed concerns at the evident knowledge gap amongst primary care services, identifying a need to rectify this but with a fear of the lack of capacity within the surgery. Newcastle Young Carers shared with the workshop group that they provide training highlighting the gap in information provision as no one knew this.

“It feels like we have a massive knowledge gap and we're really worried about capacity and the number of referrals that may come from doing some work to identify carers.”

3.6.3 What are the three key considerations that health and care need to build into future strategy and services for carers in order to best address the issues raised within conference discussions?

Three key areas were identified for health and care to consider and, in addition, some further considerations were also discussed:

- Instead of a CCG and local authority strategy document there should be an action plan that organisations can sign up to. The identification of more carers would be a key factor in the action plan and only then should services be commissioned for carers.
- Considering carers champions within GP practices and practice clusters.
- The need for improved communication between services and the integration of primary care and social care.

Other considerations for health and care to build into future strategy and services for carers included:

- Exploring a carer hub for information provision that can be accessed by all.
- The need for more VCS organisations involved in time out events to learn more about what services are available.
- Exploring longer term contracts for VCS organisations to enable them to provide a more consistent service long term.
- Focusing on what solutions can be put in place in relation to the top five carers' priorities.
- The need for carers' breaks to be more accessible.
- The need for better assessments and carer identification.
- Joint commissioning of services could improve integration and provide a more joined up system.

3.7 Carers' issues

The issues and needs of carers were discussed by one table with representatives from organisations and groups including:

- Carers
- NHS Newcastle Gateshead CCG
- CCG lay member
- Newcastle Carers
- Newcastle Disability Forum

3.7.1 What is good about carers' experiences within your own organisation?

The workshop group discussed what creates a good experience for carers informed by carer opinions and experiences.

Most importantly, personal contact with a carer provides a good experience and the availability and accessibility of information. Much discussion is given to the need for online information resources, which are important, but there should be recognition that carers would like the option of how best to access information for their individual needs and circumstances. The availability of printed information as well as face to face advice or a telephone line is also important for carers accessing advice.

Carers also see multiple organisations working together to provide carers services as a positive experience, particularly when the services are responsive to carers' needs. This also includes the need for organisations to share information.

Providing activities for carers to attend away from their caring role is also essential to offer a break, providing they are easy to access and easy to register for.

3.7.2 What are the three main change proposals from the conference you will take back into your organisation?

The discussion focused on the general change proposals rather than actions to take back to participants' specific organisations and these included:

- The need for integrated working between service providers, CCG and local authority service providers.
- Carers save the care system a lot of money and this should be taken into consideration when funding is identified for more carer support.
- There needs to be more education to recognise carers and their needs in all sectors and organisations. This is particularly true for education settings to help schools and colleges identify carers and encourage them to come forward for support.

3.7.3 What are the three key considerations that health and care need to build into future strategy and services for carers in order to best address the issues raised within conference discussions?

The discussions identified three main considerations for health and care to build into future strategy and services:

- The need for bigger and better resources to be put into communication about carers services. This input is needed quickly as there is a clear gap in provision and accessibility.
- The need for easily accessible information for carers and professionals about carers' issues and for this to be available in multiple formats.
- Ensure that health and care are listening to the people who have the experience – frontline staff, service providers and carers have valuable knowledge.

3.8 Key feedback points

During the conference, each workshop discussion group was asked to provide one key discussion point from their table:

- **Issues and needs of young carers** – There has been a lot of discussion today about identification but the structures we have in place are sometimes a barrier for young carers coming forward. Terms such as ‘assessment’ do not help. We need to be more pro-active, spotting the warning signs earlier and reaching out to young carers, using a language they understand.
- **Issues and needs of adult carers** – It was identified that the sector could benefit from the production of a vision for carers that is not restricted by resources and that focuses on what can be done. In addition, information provision for carers and sharing information between organisations is a simple idea but the current system is preventing this.
- **Carers of older people** – It was identified that there is a need to raise awareness of carers amongst communities. In addition, there was recognition that information sharing across organisations is important and frontline staff should be more proactive in referring and signposting carers for further support. It was recognised that information governance can present issues that are difficult to overcome.
- **Carers of people with mental health concerns** – There should be commitment by all service providers to address carers’ issues for all ages and commissioners should promote this within contracts for service providers. Clarifying the roles and responsibilities of the statutory sector and VCS organisations was also important.
- **Carers and primary care health services** – Primary care health services would like to see the introduction of carer champions to support their work. It was also identified that primary care would also like more support from VCS organisations in relation to carers. In addition, practice managers should have a more collaborative approach to addressing carers’ issues.
- **Carers’ issues** – It was identified that funding, communication and information and advice were important factors in addressing carers’ issues. There was also recognition that service improvement should be an outcome of the conference.

Section 4 - Panel discussion

4.1 Panel discussion

The panel discussion took place at the end of conference and each workshop group submitted a question to be answered by the panel. The panel was chaired by Jill Remnant and included:

- Jackie Cairns, Director of Planning, Delivery and Transformation, NHS Newcastle Gateshead CCG
- Dr Karen Nielsen, Older people's mental health, care homes and dementia lead, NHS Newcastle Gateshead CCG
- Dr Guy Pilkington, Chair NHS Newcastle Gateshead CCG
- Steph Edusei, Chief Executive, Healthwatch Newcastle
- Paul Brownlee, Service Manager, Young Peoples Services, Newcastle City Council
- Fiona Richardson, Carers Lead Officer, Newcastle City Council
- Katie Dodd, Chief Executive, Newcastle Carers

4.1.1 Panel question: Given the concerns of young people about local authority intervention, who is best placed to assess their needs as carers?

As the Service Manager for Young People's Services, Paul Brownlee noted that the local authority currently undertakes a wide range of assessments in relation to children and young people which can contribute to the early identification of young carers and this is not the local authority's responsibility alone. In relation to carer's assessments, the local authority has a number of local partners, including PROPS, Barnardo's and West End Youth Enquiry Service (WEYES), who carry out assessments of young carers' needs and the organisation working with the young person can continue to do so through the assessment.

It was also noted that in the future, investment in a single service that will deliver an offer for young carers is a possibility.

"In order to influence that service, certainly around the assessment process, we're engaging with an organisation called Roots and Wings who will make sense of a consultation with young people around the service they would like to see and about the assessment process. It will focus on their needs and wishes to make sure it's a useful experience to them." Paul Brownlee

It was also noted that basic principles need to be established in the assessment process including no more assessment than is needed and that the assessment should lead to better outcomes for young people and clearly focus on the needs of young carers.

Steph Edusei added to the discussion noting that, from a young person's point of view, the terminology used during formal processes can be off-putting and there needs to be a change across the system in the language used.

“Particularly from a young person’s point of view, the terminology used isn’t good, for example, the term assessment means something particular to young people.” Steph Edusei

A number of delegates evidenced this point with one participant noting the fear and negative connotations attached to terms such as assessment as being a major barrier to young carers coming forward to receive support, particularly when associated with the local authority. Another participant added that the terminology is not just an issue for young people but also for many adult carers.

“Many people will say they don’t want a carer’s assessment because they think it’s about their ability to care rather than assessing their needs as a carer.” Conference delegate

Another participant identified that, in addition to the language issue, there is a need to change the way assessments are carried out to be a more participatory process. Young people should be encouraged to complete assessments alongside a professional instead of a professional speaking for the young person and proposing a pathway they think is most suitable. The young person should have more control in the process to ensure the assessment is a true reflection of the situation.

In response to participants’ comments, it was noted that although the ideal position is to reduce stigma and fear of statutory services, there is still a need to recognise the importance of safeguarding routes, particularly if a young person is identified as living in circumstances which are harmful to them, to ensure their safety.

4.1.2 Panel question: Where are we on the pathway to joint commissioning and shared budgets?

Dr Guy Pilkington noted that progress has been made culturally to ensure that all future changes should be considered jointly across health and social care. The need to consider a co-production model to commissioning is now evidently being used where carers, services users, VCS organisations and other partners and stakeholders are involved in the design of services.

“Everything that lands at our door from now on - the first question will be should we do this jointly?” Dr Guy Pilkington

Dr Guy Pilkington provided an example of joint commissioning currently in progress. The CCG and local authority needed to consider services to support the emotional wellbeing of children and families but there was a recognition that this should not be done alone. Although this work is at the very beginning of a long process, there is an agreement amongst the CCG and both Newcastle City Council and Gateshead Council to work collaboratively to commission for children and families, taking a families approach to emotional wellbeing and, within this, is a commitment to budget jointly. It was noted that collaborative commissioning should lead to pooled budgets to design a single system.

Jackie Cairns noted that joint commissioning is actually at the end of the process and that currently there is a need to be committed to joint strategic planning.

“We’re convinced that the problems the system is facing can only be solved by a whole system response so we have to start from the point of having a shared vision and a shared strategy for how we deliver health and care across Newcastle.” Jackie Cairns

Adding to Dr Guy Pilkington’s example of joint commissioning, Jackie Cairns outlined another instance of joint commissioning for Speech and Language Therapy services in Newcastle whereby current services are commissioned by five different organisations or mechanisms. In terms of the budgeting arrangements, it was unknown at this stage exactly what the position would be in terms of finances but there was a recognition to explore problems and solutions together.

“We’re committed to exploring the problem jointly and exploring the solutions jointly. I think joint commissioning is actually the end part for me.” Jackie Cairns

It was also noted that the emergence of the Better Care Fund would enable the CCG and local authority to consider the joint allocation of resources to deliver outcomes across the system.

In response to the panel, a participant noted the ongoing innovative pilot in Greater Manchester to integrate commissioning and services and was keen to explore whether Newcastle had considered such an approach.

Dr Guy Pilkington explained that, through the Core Cities network, Newcastle has connections with Greater Manchester and there have been site visits to explore some of the programmes that are ongoing in the area. However, it was noted that the current pilot for collaborative commissioning may not be as straightforward as first assumed as the existing regulatory regime of the NHS still applies, including the accountability of different agencies to different tiers of authority. Despite this, the principles of the devolution agenda are of interest to Newcastle.

“Our integration agenda needs to increasingly think about new models of care and, if you’ve had a chance to look at the NHS Five Year Forward, you will see that through new models of care, we will be doing some very significant grass-roots integration of health and social which will begin to define our model of integration.” Dr Guy Pilkington

4.1.3 Panel question: What investment will be made to enable integrated working with regard to carers?

Jackie Cairns noted that it was unknown how much investment would be available for inter-agency working but that there is a real need to consider the finances of all organisations to ensure the best value for services. At present, there is more to be done to identify strategic priorities which can then determine the investment required.

4.1.4 Panel question: What change in commissioning behaviour will be necessary?

As one of the key questions in the panel discussion, comments were invited from all panel members.

Fiona Richardson began by supporting the previous comments made by Dr Guy Pilkington by echoing that much work has already been done to change commissioning behaviour, shown by the ongoing projects. Jackie Cairns added that there is a need for all organisations involved in commissioning to remain open and honest about their position to enable joint working.

Steph Edusei noted that commissioners always aim to go a good job but that despite good intentions, all organisations are accountable to a higher tier of regulatory practice. Inevitably, organisations will also be accountable to different bodies which can create issues when new demands are placed by those bodies. The solution is to provide a genuine commitment to collaborative working and to endure through austere times.

Adding to the argument for joint commissioning, Paul Brownlee noted the need for more co-production and co-delivery of services which should take a preventative approach to care provision. Paul Brownlee also recognised the need for greater engagement with service users and families around commissioning arrangements to better understand what works well and what could be better for communities.

Katie Dodd provided a very different perspective as a direct service provider for carers but agreed with previous comments about the need to be open and honest about commissioning arrangements. It was noted that this can be difficult when a key stakeholder is the current service provider and there is also a need to improve the co-production process to ensure it is true co-production.

“It’s really difficult when they [commissioners] need to commission services to have that open and honest conversation with us when there is that transparency about the potential advantages of other providers, so there’s a real dilemma about how we approach that and have that conversation.” Katie Dodd

A participant added to the discussion on joint commissioning, noting that within an organisation it is easy to feel significant changes to practice have been made but the real test should be whether the service users feel that the service has changed.

“I think that’s the ultimate test of whether we’ve changed, does the change deliver better and more responsive services to the end user.” Conference delegate

Dr Guy Pilkington agreed with the participant’s response by adding that high-level commissioning is necessary to provide a system-wide approach but there are many layers to commissioning. Arguably, the lowest level of commissioning is a conversation between an individual and someone providing advice, guidance or support, and if commissioning is considered in this way, patients can be kept at the centre.

“I think we need to think of commissioning in that way at every single level and it is to do three fundamentals, which came out in the NHS Five Year Forward View. One is it’s to do with being better at preventing, it’s about changing that conversation with individuals and communities and it’s also about changing the locus of control and shifting it away from professionals to individuals.” Dr Guy Pilkington

4.1.5 Panel question: How can we improve information sharing, communication and cooperation across the system?

Dr Guy Pilkington began by noting that information sharing is a big concern, despite current technology, as the main issue arises from information governance. It was noted that the demarcation of information between organisations has become more pronounced since the Health and Social Care Act 2012 but the concerns regarding confidentiality are legitimate. It was noted as essential to allow individuals to have control over their information and a rush to solve this problem could destroy important principles in the health and care system, such as, the right to see a GP confidentially.

Debating this issue, Steph Edusei provided a different perspective to information governance, noting that an individual should own and hold their information. Although recognising that not all individuals would be able to do so, there is a need to realise that the information is not owned by an organisation but by the individual. This would enable individuals to share their information with whomever they choose including, for example, their GP or their social worker.

Katie Dodd evidenced the need for a mechanism to share information:

“For us, one of the things we ask all carers when they register with us is their GP and if we can have their permission to pass that detail on to their GP and invariably people give us that information and they say yes. We just don’t have the mechanism to be able to pass that information on.” Katie Dodd

4.1.6 Panel question: What ideas does the panel have of how we can provide support to carers earlier so that we are better at helping them before they end up in crisis or a key point in transition?

Dr Karen Nielsen began by noting that advance care planning is an important, proactive and participatory method to prevent crisis situations from developing. With particular illnesses or conditions, there is often a pathway that can, to some extent, be predicted and, therefore, planned for. This allows carers to have difficult conversations in a timely manner when they have time to think about their decisions. Despite this, there is still a need for crisis resources as, inevitably, crisis situations cannot be completely prevented. There was a recognition that, as professionals, more needs to be done to put care plans in place.

“We’re not very good at doing that at the moment, we try to be very optimistic and upbeat and pretend that things aren’t going to happen but maybe we should be a bit more honest. It’s a change in approach but we need to plan ahead and have contingencies.” Dr Karen Nielsen

Although in agreement with Dr Karen Nielsen, Katie Dodd also noted that there needs to be more of a focus on the needs of the carer and not just the person they are caring for. Jackie Cairns noted that it should be a responsibility of everyone to 'think carer', to raise awareness, to make it clear that being a carer is a respected role and to be aware of the entitlements available.

4.2 Further panel questions

Due to time constraints at the Conference and the need to provide detailed responses to all questions, not all questions could be answered on the day. The panel made a commitment to ensure all remaining questions were provided with a response and can be seen below.

4.2.1 Panel question: How will the CCG/LA change commissioning behaviour in relation to this conference?

The CCG and Local Authority are already always thinking about co-production and integration. We want our processes to be more aligned and we recognise that the best solutions aren't created by just one organisation; they are created by commissioners, providers, stakeholders, carers and their families.

4.2.2 Panel question: Where are we on the pathway to joint commissioning and shared budgets for carers in Newcastle?

The CCG and Local Authority are currently working together to jointly commission the services for carers in Newcastle. The information gathered from the conference will feed into what that specification and service will look like.

4.2.3 Panel question: If we're moving to one CCG, but we have two LA's, how will that work if they have different budgets and different priorities? How can we ensure integration?

Health and Social Care integration will be on the Local Authority footprint and the CCG budget will be used across both Local Authority areas.

4.2.4 Panel question: Recognising the importance of early intervention there should be time to reflect and also for carers to give themselves 'permission' to take time out or get support and not feel guilty. How can this be remedied? What can be done to give more support to the cared for so carers get a break?

Prevention is better than a cure and this applies to caring too. Early identification is preferable, and in theory should be relatively easy as whilst the majority of carers won't be in contact with social care, they will with the NHS at some level. How organisations and individuals respond to carer specific needs once they have been identified can make a difference.

Good quality, affordable, flexible and accessible services for service users and patients is undoubtedly beneficial to carers, sometimes providing them with a break. But this alone is insufficient. You also have to bear in mind that the majority of people don't have any support from social care services, so people manage their own situation.

There is plenty of evidence to demonstrate that providing carer specific information and support provides real and lasting benefits therefore making economic sense. There's not a single solution and it's not a 'one off' intervention as caring usually lasts a number of years; it's often referred to as a 'caring journey' and it can be a very difficult one. Caring can fluctuate and so the carer support has to be based on their needs.

Newcastle Carers is the Newcastle Network Partner of Carers Trust, therefore we deliver a service that is based on the Carers Hub model of comprehensive carer support. In our experience this is about looking at the issues through the carers lens. It's about recognising and responding to their needs, from their perspective. Carers can no longer be viewed as 'the mum of, the son of', they have equal rights and the Care Act enshrines this.

4.2.5 Panel question: What investment will Newcastle commissioners make to supporting interagency work supporting carers and effective communication and information sharing – to avoid having to have another conference and the same discussions in a couple of years?

We are already embarking on joint commissioning as detailed earlier. Our Better Care Fund plan recognises the importance of carers and the need to make sure we invest our shared resource in a manner that supports interagency work and information sharing. In terms of future engagement we are hopeful that any large scale communication events are seen as a positive continuation of open dialogue and sharing of ideas between stakeholders and commissioners.

4.2.6 Panel question: What is going to happen tomorrow to implement change needed?

As a result of the conference, the importance of the needs of carers and the responsibility we all have has been highlighted and increased. As commissioners, we will use the information gathered from the conference to agree and respond positively to those issues.

4.2.7 Panel question: What ideas do the panel have for how we can provide support for carers earlier so that we are better at helping them before they end up in crisis and at key points of transition?

The role of primary care was highlighted as key in terms of support but also early identification of carers. We are looking to develop a Carers Champion in each of our practices who will act as awareness raiser and sign poster to ensure we are able to offer the right support at the right time. They will help us to identify health

and wellbeing support needs and to understand from a carer perspective how we best address them.

4.2.8 Panel question: What happened to the Admiral nurses/Dementia Advisors?

The CCG is intending to invest to support the appointment of Specialist Dementia care Nurses to work across the acute care sector. We are working with the Alzheimer's society to explore ways of potential collaboration

4.2.9 Panel question: The LA has a mandatory duty to assess young carers and identify their needs. What measures are in place to promote services to meet their needs?

Recent training for social care staff with regards to the Children and Families Act 2014 and Care Act 2014 has included specific reference to young carers and the services available to them through our statutory offer and within universal services. Information regarding the offer to young carers and service provision can be found on the local authority website and in leaflet form for both professionals and young carers

4.2.10 Panel question: Given the concerns of young people around LA intervention, who are they best people to assess their needs?

We are currently working with young carers and young carers services to determine what exactly young carers want and need in order to enable and support them which includes consultation about young carers needs assessments. The work is being carried out by a third party and the outcomes from the engagement and consultation process will be used to determine who is best placed to assess their needs

4.2.11 Panel question: How can we improve communication and co-operation between services?

We all acknowledge that our systems should be aligned better so they can talk to each other. We will encourage direct communication and co-operation as part of pathway redesign and within our formal service agreements. It is hoped the introduction of carer champions into general practice will also help improve connection and communication.

4.2.12 Panel question: How can we share information with other organisations while keeping information governance in mind? How are health and social care really going to work together to support carers? E.g how will the information from a carers assessment be shared across the system to prevent carers having to repeat their stories to many professionals?

We need to work out the best ways to share information at the right time with the right people and with the right permissions. We will work with information

governance colleagues and partners to understand more fully the needs, limits and possibilities for information sharing.

4.2.13 Panel question: With the new legal responsibility, will there be any more funding? If not, what happens next?

Local government has faced unprecedented cuts over the last four years that have impacted dramatically on social care and its capacity to deliver. Local authorities have responded by prioritising the adults and children's social care budgets, and pursuing the efficiency agenda with vigour and innovation. The short-term looks increasingly difficult, as the scope for further savings is now reduced and the medium-term outlook for health and social care is extremely challenging. In the longer term, more resources need to be brought into the health and social care system. Exactly how that should happen needs to be the subject of an honest, public debate, that examines the trade-offs for public services.

Section 5 - Conclusions

5.1 Summary of findings

Below is summary of the main themes emerging from all of the workshops.

5.1.1 Early identification and prevention

One of the main topics discussed across all workshops was the need to identify and support carers early to prevent crisis situations developing. Much of the discussion in all workshops centred on the need to carry out identification of carers in a sensitive and constructive way, ensuring a supportive environment is provided so individuals are able to confide in health and social care professionals. Such staff could also be encouraged to look for other signs that an individual is providing care, for example, young carers may suffer with anxiety and depression caused by caring responsibilities.

Another associated topic identified was the need for health and social care professionals to ask the correct questions when speaking with carers and the person they are caring such as “who does the shopping?” instead of directly asking if they are a carer. All workshop groups also discussed the need for a continued focus on services being proactive in identifying carers. Many individuals would not immediately identify with the label of ‘carer’, seeing themselves as primarily a mother, father, son or daughter.

Ensuring early identification would also aid prevention and all workshop discussions recognised that early access to support and advice resulted in fewer crisis episodes. The ability to support carers early would ensure the correct advice, information and services are in place for that individual and would also allow for emergency care planning, meaning that when a difficult situation arises, support is already in place for the carer and the ‘cared for’. Planning for care during a crisis not only supports the carer and ‘cared for’, reducing the negative impact, it also benefits the care system by providing support triggers to deal with the situation which ultimately saves costs to services long term.

The workshop focusing on young carers particularly acknowledged the need for more involvement of schools in identifying carers and the primary care workshop recognised that GPs and other health care professionals can find identification of carers difficult.

5.1.2 Collaborative working

Another main topic discussed across all workshop groups was the need for greater collaborative working across sectors and organisations. It was recognised that health and care professionals are often unaware of the services available for carers and can presume that there is a lack of provision. The reality, however, is that a wide range of services do exist, but the fragmentation that exists means it can be difficult to navigate and access services. All discussion groups felt it was important for professionals from all sectors to know what services are available and to refer to appropriate organisations.

Discussions centred on the need for collaborative working between healthcare, social care and VCS organisations, particularly in relation to the need for a carer's GP to be aware of the issues they may be facing. To enable this collaborative working to take place, there was recognition that there should be greater clarity of the roles and responsibilities of different sectors, organisations and, within statutory services, teams.

Sharing information across organisational boundaries was also seen as a way to support carers. In practice, this could mean a carer's information could be given to all relevant support agencies allowing carers to access multiple support services whilst not being repeatedly asked for the same information. Shared information could also lead to more practical solutions as it could allow professionals to proactively support carers rather than support on a reactive basis.

Although shared information was seen as essential in supporting carers, there was recognition that information governance regulations can create a whole range of issues and there was a need to find innovative solutions to allow all sectors to work together.

It was suggested that greater training and awareness amongst staff in all sectors and organisations could contribute to greater collaborative working. Training programmes that use the experience of a variety of organisations as well as involving carers could provide a way to improve carer identification and support.

The role of primary care within collaborative working was discussed amongst a number of workshops, recognising that GPs can often be the missing link in the identification and support of a carer. It was suggested that a protocol for working with primary care professionals could be developed to provide greater links when supporting carers.

Specifically discussed in the primary care workshop, there was a suggestion to include VCS organisations in GP Time Out events to increase collaborative working as well as having a Carer Lead within each practice to ensure the carer agenda is at the forefront of primary care. There was also a suggestion to have a Carer Lead for a cluster of GP practices which could provide links to VCS organisations.

5.1.3 Information provision for carer issues

The provision of information about general carers' issues, both for professionals and carers, was also discussed within all workshops. Linked to the need for collaborative working, it was also recognised that professionals within the care sector often do not have access to service information or issues-based advice specifically for carers.

One of the positive experiences for carers is the ability of support services to provide information. In many cases, carers are not able to access information in a timely manner and, alongside their caring responsibilities, finding the correct advice can be very stressful. Many organisations offer to help carers to find the right information and advice and, therefore, alleviate their stress.

Multiple discussion groups identified the need for a 'one stop shop' for carers' information about support services, conditions and illnesses, assessments and any

other relevant topics. It was also suggested that there should be accountability for information provision to ensure it is kept up to date and accurate.

In relation to the practicalities of information provision, most workshop groups discussed the need for a website to be developed that would have all information in one place. Although this was a preferred solution for many professionals, a number of carers stated that printed information is also very useful as well as valuing the opportunity to speak to a professional in person to receive advice or information. The need for information to be available via multiple platforms was seen as crucial. Another practicality identified was the need for information to be available in a variety of languages to address linguistic barriers to carers receiving support.

5.1.4 Building relationships with carers

The final topic discussed across all workshops was the need to build a positive working relationship with carers. Ensuring that carers are listened to, valued and respected in their role is essential in identifying and supporting carers.

Discussion centred on the need to provide time within consultations, whether in healthcare, social care or VCS organisations, to build trust with an individual. For carers to speak with professionals and admit they are having difficulties can be stressful and ensuring they feel comfortable and confident to confide in a staff member is important. Ensuring a good relationship with the carer can lead to a more tailored support package which can prevent a crisis situation from developing.

A positive working relationship with carers can also help to build their confidence, encouraging individuals to step forward for further support when necessary. This increased confidence of carers can ensure they are able to get involved in care planning and decision-making which is essential in valuing their input as experts in their own lives. This was particularly highlighted by the workshop discussing young carers.

5.1.5 Reducing carer stigma

Another important finding from the workshop discussions was the need to reduce the stigma attached to caring. Most workshop discussions identified stigma as a barrier to carers receiving support. Building on previous discussion points, the need for carers to trust professionals is a key factor in reducing the stigma attached to caring, for example, services working with a whole family can build trust to reduce the fear and stigma associated with support services.

It was suggested by multiple discussion groups that a public information campaign could be a positive approach to reducing stigma. The aim would be to raise awareness of carers and carer issues so caring is respected as a role and more individuals are mindful of what caring means in practice. Information campaigns can also help members of the public to identify carers within their own family or community.

It was suggested that the idea of public information campaigns could be supported by peer mentors within schools to support young carers and raise awareness of carers' issues to young people. As well as this, carer champions, based at a local hub, could also reach out to communities to identify carers, help raise awareness of

carers' issues and provide resources for support groups whilst linking with the wider care system.

5.1.6 General support for carers

Amongst a number of discussion groups, general support for carers was identified as an important and positive service. This led from the discussion around early identification and centred on the need to ensure that beyond the early support, longer term, continuing support is provided.

Providing activities and breaks for carers away from their caring role is essential in supporting carers and preventing a crisis. The need for long term carer support and training for carers was also a key focus of discussion amongst some groups to provide continuity of care and ongoing support.

5.1.7 Accessibility

Although accessibility has been a common theme within information provision, on a wider scale many groups discussed the need for a cultural change to move away from the use of jargon and language that can create a barrier to carers accessing services.

Discussions centred on the need to use plain English and avoid jargon in all communication, whether printed or online information or during more formal assessment processes. The term 'assessment' was also discussed and there was recognition that it can often instil fear and be off-putting for carers of all ages.

Another challenge discussed, particularly by the primary care workshop, was the cultural barriers faced in identifying and supporting carers from black, minority and ethnic communities. The need for solutions to help GPs communicate effectively with all carers is essential.

5.1.8 Carer's assessments

Also discussed within multiple workshops was the process of carer's assessments. The upcoming Care Act 2014 does identify specific requirements in relation to carer's assessments but, initially, there is a need to reduce the stigma attached to carer's assessments. They can often be perceived as state intervention about their ability to care rather than as a mechanism to identify what support a carer would benefit from. Building trust and developing relationships with carers would reduce the stigma attached to carer's assessments.

In addition, after much discussion around the language used, there was also a recognition that assessments are bureaucratic and difficult to navigate whilst also being heavily-led by professionals. It was suggested that assessments could be more participatory and include the voice of the carer, ensuring they are part of the decision-making process.

Section 6 - Recommendations

6.1 Recommendations

It is suggested that NHS Newcastle Gateshead CCG and Newcastle City Council take time to analyse the findings of this research to inform the decision on the future of carers' services and inform future service specifications. From the findings, some recommendations can be made.

6.1.1 Recommendation 1: Early identification of carers

There was a clear focus throughout the conference about the need for early identification of carers along with recognition that many organisations can find this difficult.

It is recommended that:

- Organisations work collaboratively to develop processes to identify carers before crisis points are reached.
- Schools establish systems to identify young carers without solely relying on safeguarding procedures.

6.1.2 Recommendation 2: Role of primary care in carer identification and support

From the workshop findings, many primary care organisations identified that GP surgeries can find carer identification and support difficult.

It is recommended that:

- GP surgeries should name a Carer Lead within each practice to support the identification and plan support for carers within primary care. The Carer Lead should have access to training opportunities and could ensure carer issues are at the forefront of health professional's day-to-day work.

6.1.3 Recommendation 3: Collaborative working

Collaborative working was identified throughout the conference as a key factor in being able to fully support carers across sectors and organisational boundaries.

It is recommended that:

- Healthcare, social care, VCS organisations and other sectors involved in caring for carers should work collaboratively to support carers and address carers' issues.
- GPs are included in the planning and development of care packages for carers.
- Pathways and referrals between organisations should be improved to enable partnership working and to allow carers to be able to access the support available to them.
- VCS organisations should be more involved in CCG training and development events, for example, GP Time Out sessions.

6.1.4 Recommendation 4: Shared information

Throughout the conference, shared information was seen as a key method to be able to fully support a carer across multiple services, ensuring all organisations involved in an individual's care have the necessary information about their care package.

It is recommended that:

- A system should be developed to enable the sharing of relevant information across organisational boundaries. This should be designed specifically to overcome the issues created by information governance regulations.

6.1.5 Recommendation 5: Information provision

The availability of up to date information for professionals and carers about available services and carers' issues was identified in all workshop discussions as a key issue faced in the support of carers.

It is recommended that:

- An audit of the current information resources should be carried out to establish what already exists in relation to the provision of information. If current resource provision is sufficient it should be promoted to professionals in all sectors. Alternatively, if the current provision is insufficient, this should be rectified by inviting all stakeholders in a discussion about potential solutions.
- All information should be available in a range of formats and languages to ensure it is accessible to all communities and should be available online and in printed form. Personal contact with a carer should also be considered, such as telephone support.
- There should be accountability for the provision of information to ensure it is updated and published regularly.

6.1.6 Recommendation 6: Carer's assessment

Throughout the conference, carer's assessments were identified by a number of workshops as being a barrier to carers receiving support because of the stigma and fear attached to the process.

It is recommended that:

- Alongside the specific requirements identified by the upcoming Care Act 2014, carer's assessments are reviewed in relation to accessibility for carers to reduce the stigma and fear attached. The need for a more participatory approach to carer's assessments should be considered.

6.1.7 Recommendation 7: Language

The language used by professionals in the care system, particularly in relation to assessments, was highlighted as a key issue and a barrier to carers receiving support.

It is recommended that:

- The care system should use plain English when communicating to carers, avoiding jargon and terms which create barriers to accessing services.

6.1.8 Recommendation 8: Reducing carers stigma

During the conference, it was recognised that there continues to be a stigma attached to caring which provides a barrier to carers receiving the additional support they need.

It is recommended that:

- All sectors should work to reduce the stigma associated with caring to ensure it is recognised as a valued and respected role by raising awareness of carers and carers' issues.
- An information campaign is developed to raise awareness of carers and carers' issues amongst the general public, taking into account campaigns that already exist, for example, Carers Week and Carers Rights Day.

6.1.9 Recommendation 9: Mentors and champions

During the conference, it was identified that there are a range of carers' issues that could be further supported by the peers of those in caring roles.

It is recommended that:

- Peer mentors are considered in school settings to enable young people with experience of a carer role to support other young carers and raise awareness amongst other young people.
- Carer champions are considered within organisations to provide awareness raising, training to staff and to ensure carers are considered in the day-to-day work of services.
- Carer champions based in a community setting are considered to help raise awareness, contributing to the campaign to reduce stigma, but also to help with identification and support of carers in community settings.

6.1.10 Recommendation 10: General carer support

Amongst a range of workshop discussion, the need for general carer support was highlighted. With a lot of emphasis placed on early identification, it is essential that general support services are also continued and all stakeholders are aware of what is available.

It is recommended that:

- An audit of current support services is conducted to identify what support for carers is available. This should be shared with the sector to allow referrals to be made.

- From the audit, identify opportunities to improve the existing services, building on what is already available, and where gaps are identified, options are considered for services that could be provided.

6.1.11 Recommendation 11: Staff training

Some organisations, during the workshop discussions, highlighted the need for more training for staff in relation to carers and carers' issues.

It is recommended that:

- More training opportunities are provided for organisations that work directly and indirectly with carers about carers' issues. Carers or carer champions could also be involved in developing and delivering the training.

6.2 Next steps

The information gathered from the day will be used to inform the CCG and local authority carer strategy and support decisions on the specification for carers in the city.

Appendices

Appendix 1 – Conference attendees

Sally Allen	Cath Halse	Chris Piercy
Doreen Andrews	Penny Hardman	Guy Pilkington
Lucy Atkinson	Heather Harrison	Leigh Presseau
Clare Atkinson	Sandy Harvey	Alan Ramsay
Donna Aydon	Moira Hegarty	Jennifer Remnant
Joanna Bates	Iris Herbert	Jill Remnant
Martin Bell	Ingrid Herring	Fiona Richardson
Raj Bethapudi	Louise Hewitt	Sarah Ritson
Lucile Blight	Lauren Hoy	Claire Robinson
Gail Bravant	Karen Inglis	Melanie Robson
Marie Brown	Fazeelat Iqbal	Marta Rzepecki
Carol Brown	Shirley Irving	Heidi Salanki
Cathy Bull	Sue Jennings	Tracy Scott
Martyn Burn	Jacqui Jobson	Sinead Sewell
Jackie Cairns	Carol Kaikavoosi	Phil Smith
Christine Calbraith	Rima Karam	John Snaith
Daniel Carey	Shabana Khan	Norah Stevens
Doreen Chananda	Lisa Langford	Veronica Stonor
Kieran Conaty	Lorraine Lentell	Donna Stott
Paul Cooke	Jenny Low	Tracey Stuchlik
Judith Cronin	Helen MacDonald	Dr Phil Taylor
Sue Curry	Ean MacKellar	Mandy Taylor
Ewan Dick	Nicola Mansfield-Jones	Colin Taylor
Alan Dobson	Jen Manuel	Alison Thompson
Katie Dodd	Andrew Marchant	Sue Thompson
Philipa Dodds	Julie Marshall	Helen Walton
Nicci Donnelly	Alison McDowell	Chris Wass
Barbara Douglas	Caroline McGarry	Deborah Webster
Laurie Doyle-Davies	Ann McNulty	Ewen Weir
Dan Duhryn	Felicity Mendelson	Rachel Whitehouse
Steph Edusei	Ernie Miller	Teresa Wildman
Anne-Marie Fell	Helen Milner	Cynthia Williamson
Elizabeth Fletcher	Sarah Morris	Dawn Wilson
David Forrester	Sheila Mulligan	Susan Wilson
Gill Foster	Steve Nash	Oliver Wood
Denise Fraser	Mary Nicholls	Alex Woodmass
Nicola Gannon	Helen Nichols	Michele Wright
Tracy Gardener	Karen Nielsen	Andrew Young
Sharon Gaughan	Annemarie Norman	Dr Ponna
Alan Gowers	Amy O'Brien	Brenda Walker
Jayne Guppy	Christianne Ormston	Scott Vigurs
Tracey Hall	Angie Orrick	
Sean Halliday	Karen Parkinson	
Alison Halliday	Rachel Parsons	

Appendix 2 – Conference agenda

Morning session		
Registration, tea and coffee		9.30am – 10am
Welcome	Dr Guy Pilkington	10am – 10.10am
Keynote speaker	Ewen Weir Director of Wellbeing, Care and Learning Newcastle City Council	10.10am – 10.40am
Primary Care and Carers	Dr Raj Bethapudi GP Carers Champion	10.40am – 11.00am
Living my life: an insight into a life caring for someone.	Open Clasp Theatre Company	11.00am - 12 noon
Lunch		12 noon – 1pm
Afternoon session		
Young Carers and introduction to young carers story	Paul Brownlee Service Manager, Young Peoples Services	1.00pm – 1.20pm
Short discussions on reflections from the morning session Tables to discuss three main questions:		1.30pm – 3pm
<ol style="list-style-type: none"> 1. What's good about carers experiences within your own organisation? 2. What are the three main change proposals from the conference you will take back into your organisation? 3. What are the three key considerations that health and care need to build into future strategy and services for carers in order to best address the issues raised within conference discussion? 	Led by Dr Guy Pilkington	3pm – 3.15pm

Panel discussion – introduced by Jill Remnant	Dr Guy Pilkington Dr Karen Nielsen Dr Raj Bethapudi Katie Dodd Steph Edusei Paul Brownlee	3.15pm – 3.45pm
Final thoughts	Dr Guy Pilkington	3.45pm – 4pm