

Caring...it's everyone's business

Thursday 23 November 2023



Conference Report

Fiona Richardson

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Newcastle City Council

Acknowledgements

I'd like to thank everybody who gave their time and energy to the planning, preparation and delivery of this event and to everyone who attended and fully participated in the day. The energy, enthusiasm and commitment to supporting carers was more than apparent.

In particular I'd like to thank Geof, Lynne and Jak who shared their caring stories through conversation and film and Catherine who shared her caring story through poetry. This gave me and the audience first hand insight as to what it means to be an unpaid carer in Newcastle.

Fiona Richardson

Summary

Over sixty people from various personal and professional backgrounds attended the conference, the first to happen in Newcastle for a number of years.

The aim of the conference was to determine how carers in the city were identified and engaged with, areas of good practice and areas for improvement with a view to laying the foundations for a carers strategy and delivery plan for the city and improve outcomes for unpaid carers.

The conference included presentations by keynote speakers from Adult and Children's Social Care, Newcastle City Council as well as from Newcastle Carers but most importantly, from carers themselves through a variety of mediums.

Tabletop exercises throughout the day offered delegates the opportunity to share good practice and innovation as well as identifying areas where improvements could be made, why and with/by whom.

Key priorities identified included raising the profile and awareness of unpaid carers across the city, the need for change, regular conversations and updates from and with carers and carer involvement at all levels in all service provision to support and enable this change to happen.

Key learning points linked to information, communication, duplication, complexities of the system and inconsistency in approach highlight the need for

- A clear suite of options in terms of support available to carers including those with eligible needs.
- Information and advice to be readily available in different formats to suit different stages in the caring journey.
- Better understanding of what it means to be a carer – the term isn't always recognised or accepted by those with caring responsibilities.
- A system that is simple and straightforward rather than complex and difficult to navigate.
- Consistency in approach across all areas of service provision.
- Referral not signposting – positive and proactive action.
- Regular caring conversations
- A collaborative approach
- Carer involvement at all levels of service provision/delivery

The development of a multi-agency carers strategy and delivery plan is key to effectively supporting unpaid carers in the city. By working collaboratively and with carers throughout the conference, we have started the journey to identify areas of good practice that can be shared and replicated but have also identified key areas for improvement.

Key to developing a carers strategy and delivery plan for the city is the involvement of carers from the outset and commitment from all organisations and businesses to be or strive to become carer aware. This will be further prompted by the implementation of the Carers Leave Act on 6 April 2024 when it is anticipated that the numbers of carers identified, self or otherwise will increase. Until it is recognised and acknowledged that caring is everyone's business, carers will continue to be unsupported only accessing services and support at crisis point.

The development of a citywide carers partnership to take the learning from this conference forward, raise awareness of carer issues and improve health and social care services in Newcastle for carers as a system wide approach is recommended. Membership should include carers, decision makers from Newcastle City Council, NHS providers, local carers voluntary sector organisations including Newcastle Carers, PROPS Family Recovery Service, British Red Cross, Healthwatch and the Parent Carer Forum.

The partnership would be responsible for taking actions highlighted within this report and build and strengthen carer support, prioritising the development of a carer's strategy and delivery plan for Newcastle with and for carers.

These actions would support the statutory requirements of the Care Act 2014, the Children and Families Act 2014 in relation to adult and young carers and support any future Care Quality Commission (CQC) quality assurance processes

Introduction

Across Newcastle, approximately 23, 000 people provide unpaid care for/to someone who couldn't manage without their help because of illness, frailty, disability, mental ill health/mental health problems or drug/alcohol problems.

The recent ONS Census 2021¹ for England and Wales found that there has been an increase in the proportion of people caring for more hours with the North- East region seeing the most significant increase in the numbers of carers caring for more than 50 hours per week.

On Thursday 23 November 2023, Carers Rights Day, a carers conference took place. Attended by over 60 people, many of whom were unpaid carers, the conference set out to determine;

- How carers were identified and engaged with
- Areas of good practice
- Areas for improvement

The feedback from those conversations would form the basis of the [development/co-production](#) of a citywide carers strategy and delivery plan that would improve the outcomes for carers across key areas including;

- Information and advice
- Health and Wellbeing
- Identification and recognition
- Carer voices
- Young Carers
- Workforce Development
- Social and Economic Participation
- Services and support

The conference began with the poem 'Questionnaire' (Appendix 1) by award winning Newcastle poet and carer Catherine Graham.

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<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/bulletins/unpaidcareenglandandwales/census2021>

Opening remarks

Al McDowell, Director of Adult Social Care and Integrated Services, Newcastle City Council

Al acknowledged that many people with caring responsibilities do not identify themselves as a carer and that it could take a considerable amount of time, often when things reach crisis point before they access services and support. [Adult Social Care/Newcastle City Council](#) want carers of all ages and backgrounds in the city to feel valued, empowered and have access to the right support at the right time.

Her speech highlighted legal obligations in the Care Act 2014² as to how adults with needs and those who care for them are supported, including the offer of prevention, information and advice services that reduce or delay the needs for support as well as statutory adult needs assessments and carer assessments for those carers who present to social care services with an appearance of need.

Al closed her speech by confirming that adult social care services in Newcastle were working hard to support carers and those they cared for to access information and advice, services and support in the [easiest/quickest](#) way possible. Al confirmed the keeping traditional approaches such as phone or letter to do this but that the Council would be expanding that offer to include an online option, including the development of an online self-assessment tool for carers and the people they cared for which would get people to the right place at the right time and ensure that they were not passed around 'the system'.

Dr Dan Cowie, GP and Ageing Well Lead, NHS North East and North Cumbria Integrated Care Board

Dan highlighted that carers played an important role within the community, and without them, the health care system would not be able to function. He acknowledged that most of the work carers did was not recognised.

Dan referenced the NHS Commitment to Carers³ report published in 2014 that as well as the NHS Long Term Plan⁴ launched in 2019 which underpinned the

² <https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

³ <https://www.england.nhs.uk/commitment-to-carers/>

⁴ <https://www.longtermplan.nhs.uk/>

original commitments and pledged to maintain the NHS focus on identifying and supporting carers by identifying several areas for improvement. This included, carers not having to deal with emergencies on their own and having a contingency plan in place as well as identifying carers, particularly those from vulnerable communities, recognising their value and improving the support they receive, acknowledging that carers are twice as likely to suffer from poor health compared to the general population.

Dan highlighted that the NHS were raising the profile of carers in Newcastle by training and educating staff to 'Think Carer', including supportive conversations with people about their caring responsibilities, operating a carers passport scheme across the Newcastle upon Tyne Hospitals Trust and encouraging GP practices to identify carers at the earliest available opportunity and support them to access commissioned carer support services.

Who is a carer?

Fiona Richardson, Carers Lead Officer, Newcastle City Council, [Adult Social Care and Integrated Services](#) introduced the audience to the definition of an adult carer as detailed in the Care Act 2014 a parent carer and a young carer as defined in the Children and Families Act 2014⁵ respectively.

- **Adult Carer** - *Someone 18 or over who provides or intends to provide care for someone.*
- **Parent Carer** - *Someone over 18 who provides care for a disabled child under 18 for whom they have parental responsibility.*
- **Young Carer** - *A child or young person under the age of 18 who provides or intends to provide care for another person.*

Participants were also introduced to the commonly recognised working definition of a carer as

'Somebody who provides unpaid care and support to someone who couldn't manage without their help because of age, disability, mental health problems or drug and/or alcohol problems'.

It was highlighted that young carers were most likely to be providing care and support to parents, grandparents or siblings.

⁵ <https://www.legislation.gov.uk/ukpga/2014/6/part/5/crossheading/young-carers-and-parent-carers/enacted>

A picture of caring in Newcastle (Appendix 2) was presented based on information from Census 2021 showing the population of the city as 300, 123. Approximately 7% of the population, or 23, 294 people aged 5 and above are providing unpaid care and support to someone In the city, the majority of whom are providing 50+ hours of care a week.

In addition, information from the 2023 GP survey and numbers of carers registered with Newcastle Carers was also shared.

Conversation with a Carer:

Geof Ellingham



To support/enable a better understanding of what it is like to be a carer in Newcastle, a semi structured conversation (Appendix 3) with Geof Ellingham took place. Geof is a parent, works and provides unpaid care and support to his husband Alistair who, as a result of a sudden illness became visually impaired.

Geof highlighted the difficulty in being identified/self-identified as a carer and made reference to the 'label' that people are given. He said that he'd accepted this 'label' as he'd understood that it was the only way to access or receive support but said that this wouldn't necessarily be the case for all in a similar position.

Geof stressed that being offered/given information and advice at the time of Alistair's illness/hospitalisation/discharge would have helped in terms of what support was available to him as a carer as well as a clear explanation and guidance on statutory support from social care services for both of them. Geof highlighted that it had taken some time and many discussions with social care staff for a direct payment to be mentioned/offered as an option as opposed to traditional home care support which would not have met their needs. Needs had eventually been met by a direct payment which had enabled them to employ a personal assistant which complemented their lifestyle. An open and honest conversation at the outset of the care/carer journey with health and social care staff as to all options available would have reduced the time taken to meet those needs and would have helped significantly.

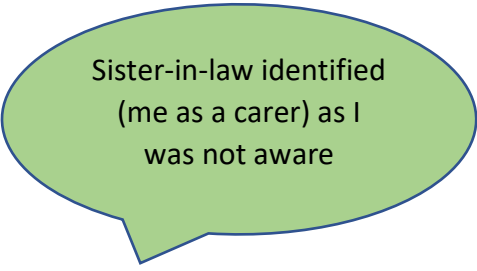
Table Exercises

Participants were asked to reflect on the conversation and work in groups on their tables to discuss the following question.

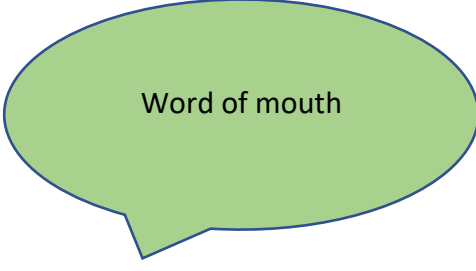
Exercise 1: What do you do (individually or organisationally) to identify and engage with carers?

Participants highlighted a number of ways (Appendix 4) in which they did this including, face to face conversations with individuals, collaborative working with other services, events, information sharing, NHS Primary and Secondary care services, Social Care services, Education, Safeguarding and through council commissioned services, including Newcastle Carers and British Red Cross Emergency Card Scheme.

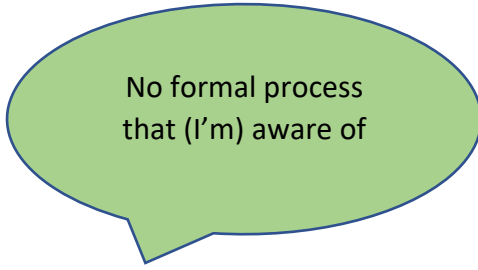
As well as highlighting the positive practices, participants, carers in particular referenced the fact that it wasn't always that easy to identify yourself as a carer and it was often down to family and friends who made the connection.



Sister-in-law identified
(me as a carer) as I
was not aware



Word of mouth



No formal process
that (I'm) aware of



Family and friends

Organisations who supported individuals through generic advice and information services identified innovative ways in which they identified and engaged with carers. This included when an individual was acting on behalf of someone, for example as their attorney or when they were applying for or seeking advice on benefits, such as Attendance Allowance or Carers Allowance.

All participants agreed that it was difficult to identify which were the best ways in which to identify and engage with carers as each person was an individual with different preferences.

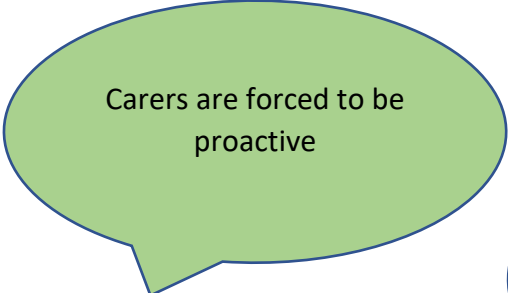
Exercise 2: What if anything from your list could let you (as an individual or organisation) or the carer down in terms of identification and engagement?

Participants were then asked to look at their previous answers and determine where they thought the [weaknesses/challenges](#) were in the approaches they'd identified from an organisational and carer perspective (Appendix 5).

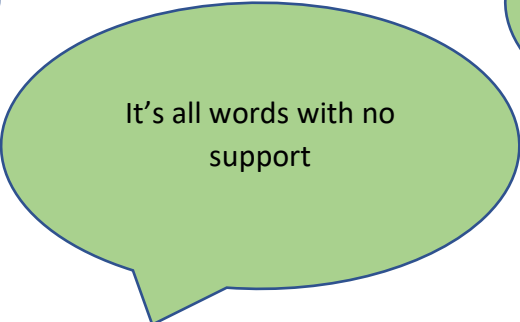
Key points included inconsistency in approach from statutory and [third sector/voluntary sector](#) service provision, self-identification was difficult as was acceptance of the term 'carer' but without this, access to support was difficult. The availability of online access to services and support counteracted the need to leave the person being cared for alone or to have to find someone else to take care of them whilst accessing the traditional support offer but, for many, digital access was an issue in terms of knowledge, cost, what to look for within a search engine and how to do this.

The groups identified that carers, despite identifying as such didn't always know where to go for support or what to look for as the offer wasn't always clear and different organisations offered multiple elements of support online and offline. It was highlighted that when carers do ask for support from services, their lack of knowledge of commissioned/carer specific services and unmanaged expectations particularly around signposting as opposed to referral often left the carer frustrated and inclined to 'give up'.

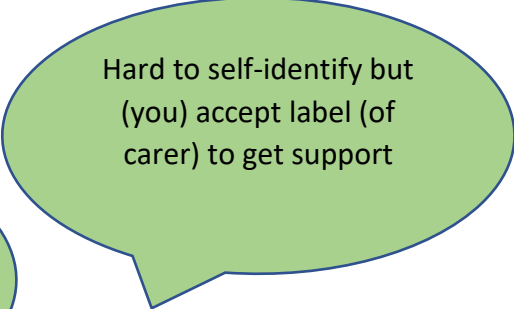
Other areas of concern included poor communication, repetition, lack of continuity, lack of understanding, lack of resources including staff time and funding and having gone through the 'system' only to find ineligibility for statutory services and support, led to carer fatigue.



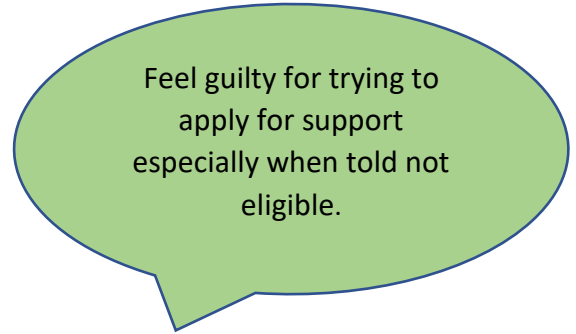
Carers are forced to be proactive



It's all words with no support



Hard to self-identify but (you) accept label (of carer) to get support



Exercise 3: What other opportunities do we have/can you see for identifying and engaging with carers?

The overall consensus was that caring was everyone's business as it was something that the majority of people will do in their lifetime and for this reason, it needed to be 'normalised' not stigmatised.

Feedback/suggestions (Appendix 6)included a regional approach to carer support services so that things were more cohesive/consistent, negating the 'postcode lottery' that many felt was present in terms of support/services offered and thereby ensuring that there were no wrong doors for carers of all ages.

Participants agreed that whilst signposting had its benefits, a more proactive approach to supporting carers was needed, including but not limited to making the referral to services or asking the services to contact carers directly. Professionals and carers were unanimous in their view that many carers who were only signposted to services would not in their experience, contact them.

In addition, it was identified that there was a need to raise the profile of carers and caring with employers in the city, highlighting the benefits of supporting and maintaining carers in the workplace. The Carers Leave Act⁶ will support the identification of carers in the workplace but how it will be applied and remains to be seen. Underpinning this and the most significant opportunity/clear message that came from the exercise is that carers need to be an integral part of this, meaningfully consulted, engaged and involved and valued as experts by experience.

⁶ <https://www.legislation.gov.uk/ukpga/2023/18/enacted>

Range of formats of up-to-date information – carers don't have the time to chase

Can we have NE carers, so it's more joined up. Having local branches makes it complicated for information

Caring needs to be everyone's business.

Advertisement – visual prompts everywhere e.g., metro, shopping centres

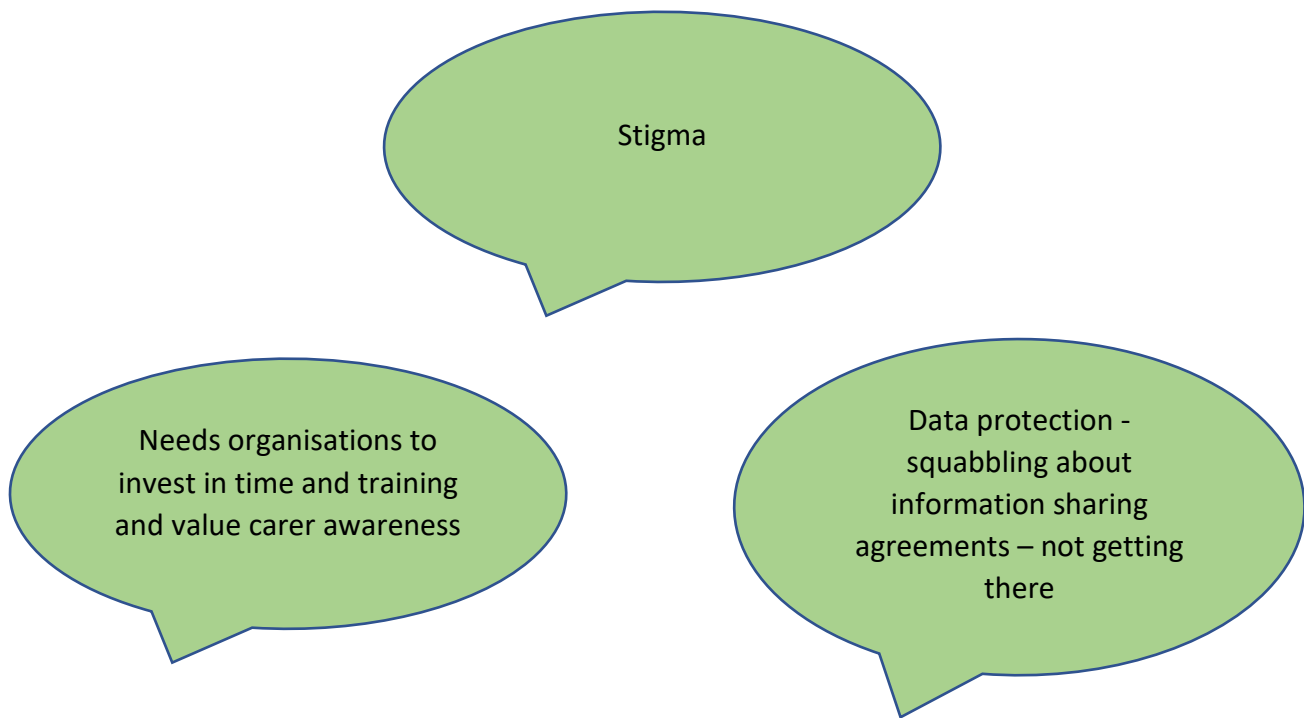
Instead of signposting – go through the steps with the carer - signposting can be great; however, (it can) also a 'go-away'.

Exercise 4: What could stop us/prevent us from achieving this/why?

Whilst participants highlighted the need to explore opportunities, they also acknowledged that in the current climate, it wasn't always that easy.

The next exercise focused on where the challenges lay in promoting the carers offer, to carers and others including non-carers, professionals and services.

Understandably, resources and capacity were key areas highlighted by participants along with timescales (Appendix 7), all agreeing that changing the mindset and implementing change(s) to support this all took time. Time to change, time and resources to invest and promote carer identification and carer awareness including training which in turn would support carers to identify and access support. Time to challenge the stigma associated with being a carer and the caring role and time to invest in marginalised communities of carers i.e., those carers who would not traditionally access or engage in carer support services for various reasons. In addition, and key to supporting carers was the sharing of information, particularly to enable carers to tell their story once and not have to repeat it but participants felt that information sharing agreements were few and far between and difficult to implement or seek agreement to.



To finalise the exercise, participants were asked to consider what they could do as a quick win to support carers going forwards (Appendix 8).

Responses included the need to offer and maintain face to face contact with carers, to ask the questions about their caring relationships and not to make assumptions about individuals and their circumstances. An example of this being that a carer had been seen with the person they cared for by a professional on numerous occasions but had never been asked about their [role/input/caring relationship](#). The need to [create/raise](#) the profile of carers by means of carers champions within an organisation, no matter how small was also identified as key.

Conversation with a Carer: Lynne Blakey

To close the morning session, a second semi structured conversation with a carer took place (Appendix 3).

Lynne told us that she was a single parent to two adult daughters, one of whom has additional health and care needs following a diagnosis of severe ME/Chronic Fatigue Syndrome given to her younger daughter at the age of ten.

Both were initially supported by Children's Social Care which included the creation of an Education Health and Care Plan (EHCP)⁷ a legal document that describes a child or young person 's educational health and social needs and

⁷ <https://www.gov.uk/children-with-special-educational-needs/extra-SEN-help>

sets out the additional support to meet those needs. The EHCp remains in situ until the age of 25 or until the outcomes related to their needs are met for the young person.

At 18 years old, her daughter transitioned into adult social care services which changed the approach and support offered. Lynne, with her professional background in Health and Social Care and with excellent knowledge of statutory legislation described accessing statutory services and support for her and her daughter as difficult at the best of times and felt that due to a number of factors she had 'fallen through the net' and had been unable to access the same opportunities as her peers.

Lynne highlighted the challenges of a complex social care system combined with her caring responsibilities as having a significant impact on her own health and wellbeing. This included having to leave a well-paid job due to lack of appropriate replacement care and support to meet her daughters long term fluctuating needs to become a full-time carer which had a knock-on effect on the family finances.

Most recently, Lynne had experienced difficulties in requesting support for her family following a change in her daughters needs/condition. This resulted in feelings of frustration for her and the lack of a named social worker for their case only compounded these feelings . Lynne felt that the difficulties she experienced could be avoided if there were clear and consistent lines of communication between families and adult social care and other agencies and named contacts and a recognition of the knock-on effect to the whole family when a child or young person has disability and complex needs that require care and support planning and intervention.

The lunch break offered participants the opportunity to visit information stalls, network with each other and view the InformationNOW image gallery on the in-house screens.

Catherine Graham set the tone for the afternoon session with her second poem 'The Washing Machine' (Appendix 9)

Opening remarks - PM

Cath McEvoy Carr Director, Children, Education and Skills, Newcastle City Council

Cath explained that her responsibilities included children's social care, education and skill and family support and with that young carer. She reminded participants of the numbers of young carers and young adult carers in the city and highlighted that the majority of those young people would be providing care and support to someone in their family and that the care provided would normally be expected of an adult.

Key findings from the recently published report by the All-Party Parliamentary Group for Young Carers and Young Adult Carers⁸ were shared with participants along with the fact that young people with caring responsibilities were unlikely to self-identify or be identified because of stigma attached to illness or disability in the communities in which they lived and the fear of social care involvement.

Cath highlighted Newcastle Carers, Young Carers Service and the work they did with families, professionals, education providers and communities to raise the profile of young carers, build relationships and ensure that young carers and their families were supported to access a young carers assessment with a specifically trained worker to help them identify and put into place measures that reduced the caring role and any negative impact it had.

Linked to this work was the commitment to support young carers and their families to prevent young carers taking on inappropriate and excessive caring roles and to ensure that young carers had access to the same opportunities as their peers.

The final ask was that participants 'think carer' and take positive action to identify and support those young people in our city with caring responsibilities.

Young Carers

The audience were shown the animation 'Rosie is a carer. Are you?'⁹. This was one of four films created by young carers aged 8-15 in partnership with Sail

⁸ <https://carers.org/all-party-parliamentary-group-appg-for-young-carers-and-young-adult-carers/appg-on-young-carers-and-young-adult-carers-inquiry-into-life-opportunities>

⁹ <https://www.newcastlecarers.org.uk/young-carers-wecaretoo/>

Creative to highlight the issues faced by young carers and make positive changes including better identification and greater recognition of young carers.



Jak (not his real name) a young adult carer shared his caring story through a short film created in partnership with Newcastle Carers¹⁰. Jak was not identified as a carer, despite having cared for his mum since primary school until he started college. He talked about his experience of being recognised as a young adult carer, the support he received and how this had benefited him. He also gave some key advice to young carers and professionals about based on his experiences.

Table exercise

Following the films, participants were asked to reflect on the key messages from the day so far and think about the following question.

How can we support and engage in better/changed working practices to ensure that carers are identified, engaged with, supported and have a voice in our systems across the following key areas ?

- **Information and advice^{11*}**
- **Identification of carers, including parent carers and young carers***
- **Support – including information, advice, services specifically commissioned and statutory support ***
- **Health - including primary and secondary health care services***
- **Wellbeing - including time out/breaks/self-care/groups/social life.**

¹⁰ <https://www.newcastlecarers.org.uk/young-adult-carers-carers-stories/>

¹¹ *Elements of the exercise needed to be removed/adapted to accommodate the changes in numbers for the afternoon sessions

- **Young carers/transitions**
- **Education and learning***
- **Employment**
- **Communities who don't traditionally access services/support**

Wellbeing

The group concluded that carers often put off or ignored their own health, care and wellbeing needs. To support and enable carers they felt that connections, particularly with supportive local networks were really important. This included local shops, employers and pharmacies being carer aware. Flexibility was key for appointments and accessing support, both of which were felt could be offered online but the more traditional approaches of face-to-face appointments/personal contact should also be made available to support choice and accessibility. In addition, more flexibility around the use of direct payments following a statutory carers assessment as well as someone checking in with them at a time convenient to the carer were highlighted as other options that could support carer wellbeing

Health and Social Care

The group concluded that identifying carers and offering support at the earliest opportunity may not always be the best option or the right time. The group felt that carers, particularly those who had been thrust into their caring role quickly such as those identified in hospitals were more likely to be focused on the needs of the person they cared for and were likely to be experiencing high levels of stress combined with information overload. The time to identify and engage with carers varied from person to person and at different stages of their caring journey. The offer of support, if declined needed to be revisited periodically to ensure that carers did not 'slip through the net'.

The group highlighted that there would be instances where a carer might never come into contact with services. If they did, for instance with their GP, it might not even occur to them to tell the GP that they had caring responsibilities. The group felt that a proactive approach by all services to carer identification and engagement would be beneficial and would ensure

that the carer was given the best advice at the most appropriate time, for example, maximising income/entitlements. Whilst many of the group knew about carer assessments, they believed they and their outcomes weren't fully understood as they were not always fully outlined or explained.

Young Carers, Education and Learning

The group recognised that schools and other educational establishments had a key role to play in the early identification of young carers, that time critical interventions were needed, and that all school staff needed to be trained to identify young carers and spot signs of masking in terms of their home lives. Key to this was getting the language right, for example, being able to ask the right questions with the right language and to listen without judgement, this supporting engagement. This they felt could be supported by trusted adults in schools and education settings who shared information appropriately and in a timely manner. The group discussed making assumptions about a young person and their familial situation and agreed that this could be detrimental to the young person and their family. Assumptions, for example, assuming that because there was a parent with a disability that there would be a young carer or not needed to be challenged.

Communities who don't traditionally access services and support

These were identified as including but not restricted to children, carers of stigmatised conditions e.g., substance misuse, refugees/asylum seekers, people with sensory needs, working age carers, older people and people with literacy challenges.

The group concluded that enabling carers from those communities to access and engage with support would involve changing culture and perspective, working hard to reduce/remove stigma associated with caring for someone, educating individuals, community champions and employers and ensuring carer friendly workplace policies and practices including flexibility around accessing support/availability of support.

All participants recognised and acknowledged that this needed a collaborative approach. When asked who else needed to be involved, 56 participants responded to the Mentimeter survey, highlighting GP's, schools, social works, employers and community organisations amongst others.

Who else should be involved?

56 responses



Asset Based Community Development and Neighbourhood Working

Karen Inglis, Community Wellbeing Lead, Adult Social Care and Integrated Services, Newcastle City Council

Picking up on the Mentimeter feedback, Karen introduced participants to Asset Based Community Development and Neighbourhood Working, explaining why we should focus on the importance of connections in neighbourhoods and communities. She highlighted the importance of building and maintaining those connections, and why services should connect with each other to enable people to get to the right place at the right time for them. Karen concluded her overview by setting a challenge to all participants to find out what was available in their neighbourhoods and communities that people, carers and individuals could access and how they would do this.

Support for Carers

Luke Bramhall, Chief Executive Officer, Newcastle Carers

Luke gave a brief overview of support for carers in Newcastle including Newcastle Carers¹², a service jointly commissioned by Newcastle City Council

¹² www.newcastlecarers.org.uk

Adult and Childrens Social Care and the NHS North East and Cumbria Integrated Care Board, British Red Cross Emergency Card Scheme¹³, PROPS¹⁴ Family Recovery Service, Skills for People¹⁵ and statutory support for carers through Adult¹⁶ and Childrens¹⁷ Social Care.

Conference Close

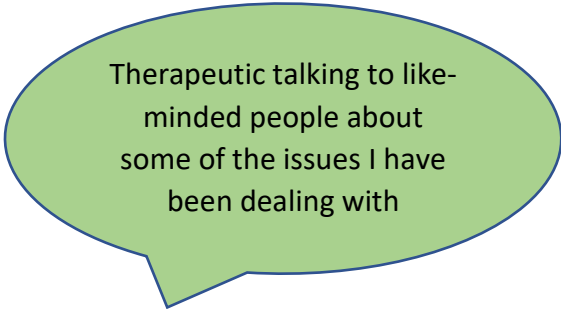
Participants, and guest speakers were thanked for their contributions throughout the day and next steps were shared. The conference was brought to a close by Catherine Graham and her final poem of the day 'Pantomime' (Appendix 11)

Feedback


Feedback from participants was requested through Mentimeter and by hard copy (Appendix 12).

What was the best part of the day?


Table discussions and exercises, the conversations with carers and the sharing of ideas and information on services and support



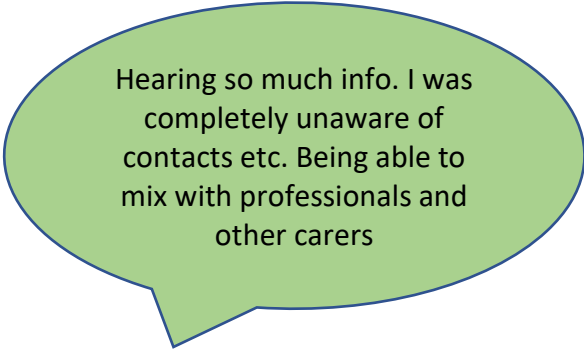
Therapeutic talking to like-minded people about some of the issues I have been dealing with



Conversations with carers and carer poetry. Time to listen and discuss



Hearing about all the different services and from the carers themselves



Hearing so much info. I was completely unaware of contacts etc. Being able to mix with professionals and other carers

¹³ <https://www.informationnow.org.uk/organisation/newcastle-emergency-carers-card-scheme/>

¹⁴ <https://props.org.uk/>


¹⁵ <https://skillsforpeople.org.uk/>

¹⁶ <https://www.newcastle.gov.uk/services/care-and-support/carers/carers-assessment>

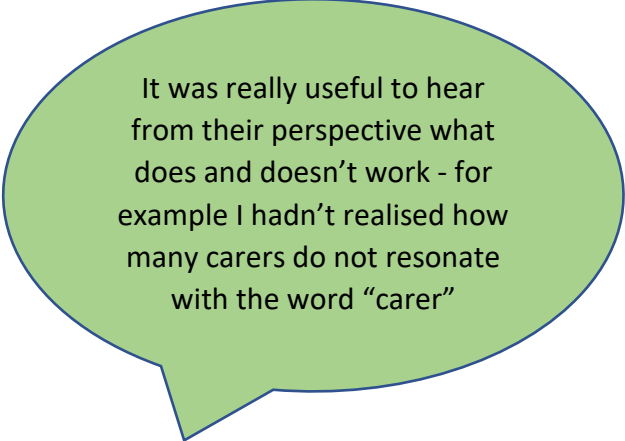
¹⁷ <https://www.newcastle.gov.uk/services/care-and-support/children/getting-help-children-and-families/are-you-young-carer>

Why was this?

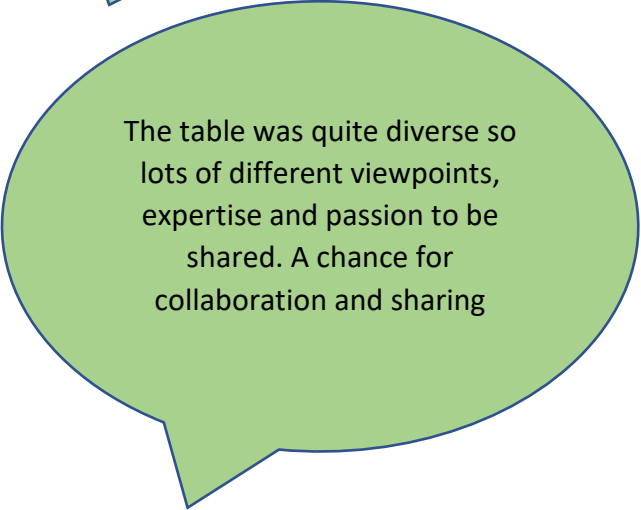
The conference offered the opportunity to listen to carers and organisations in an interesting and relaxed atmosphere and to contribute to the discussions in a positive way. Many people, including carers themselves highlighted the enthusiasm in the room to engage with and support carers.




The group discussions were very interesting and informative.
Found out about different services to support carers in Newcastle



It was really useful to hear from their perspective what does and doesn't work - for example I hadn't realised how many carers do not resonate with the word "carer"



The table was quite diverse so lots of different viewpoints, expertise and passion to be shared. A chance for collaboration and sharing



inspires me to do more and continue to develop carer support and identification

What would you like to see happen next?

Participants said that raising carer awareness with frontline staff should be a key priority along with positive action and/or acknowledgement of many of the things discussed, with actual change happening and professional networking events to support understanding and collaboration/co-production, with carers taking the lead in terms of service improvement.

Future events to update on the work being done to support carers. A separate event for young carers would be helpful with organisations and workers who specifically support young people

Action, not words. I would like the role of carers challenged by campaigning for full payment for carers (caring) and carers name change

A review and for carers to be given opportunities to feed into services and take the lead on (developing) services going forwards

The day was ran really well - thank. Brilliant discussion & involvement from everyone. I'd like to see the feedback brought together in a report & recommendations.

Participants were offered the opportunity for proactive contact from Newcastle Carers. Of the 39 people who offered feedback, 15 requested this and their details were passed to the service.

Ten participants expressed an interest in being part of future consultation and engagement sessions/events. Their details are held on file and will be shared appropriately.

Key Learning Points

- Carers need a clear suite of options in terms of support available including those with eligible needs.
- Information and advice must be readily available in different formats to suit different stages in the caring journey.
- The term carer isn't always recognised or accepted by those with caring responsibilities.

- The system is complex and difficult to navigate
- There are inconsistencies in approach across all areas of service provision and much duplication
- Referral not signposting – positive and proactive action
- Regular caring conversations

Conclusion

There is a real appetite for services/organisations in the city to identify, engage with and support carers across Newcastle but that this is not a one person/one organisation task and needs a collaborative approach with carers involved from the outset and at every stage in the process.

Caring is everyone's business. The impact of not caring for carers stretches far wider than the individual. The cost of lost workdays to employers and carers alike, health conditions directly and indirectly associated with caring roles which in turn put pressure on NHS services at primary and secondary care. The additional costs associated with caring at a time where carers are experiencing financial hardships as a direct impact of the cost-of-living crisis can be seen locally, regionally and nationally.

The development of a multi-agency carers strategy and delivery plan is key to effectively supporting unpaid carers in the city. By working collaboratively and with carers throughout the conference, we have started the journey to identify areas of good practice that can be shared and replicated but have also identified key areas for improvement.

Key to developing a carers strategy and delivery plan for the city is the involvement of carers from the outset and commitment from all organisations and businesses to be or strive to become carer aware. This will be further prompted by the implementation of the Carers Leave Act on 6 April 2024 when it is anticipated that the numbers of carers identified, self or otherwise will increase. Until it is recognised and acknowledged that caring is everyone's business, carers will continue to be unsupported only accessing services and support at crisis point

Recommendations

The development of a citywide carers partnership to take the learning from this conference forward, raise awareness of carer issues and improve health

and social care services in Newcastle for carers as a system wide approach is recommended.

Membership should include carers, decision makers from Newcastle City Council, NHS providers, local carers voluntary sector organisations including Newcastle Carers, PROPS Family Recovery Service, British Red Cross, Healthwatch and the Parent Carer Forum. It is anticipated that other organisations/businesses would be involved as/where appropriate.

The partnership would be responsible for taking actions highlighted within this report and build and strengthen carer support by prioritising the development of the carer's strategy and delivery plan for Newcastle, taking into consideration carer feedback from the local carers survey and the Survey for Adult Carers England, outputs of which are currently being collated.

These actions would support the statutory requirements of the Care Act 2014, the Children and Families Act 2014 in relation to adult and young carers and support/evidence future Care Quality Commission (CQC) quality assurance processes

Appendix 1 – Poem - Questionnaire – Catherine Graham

Questionnaire

When did I become a Carer?

Do I consider myself to be full-time?

Is my role rewarding financially?

Have I been offered support?

What, if any, are my plans?

Where do I see myself next year?

Am I overwhelmed by the responsibility?

Do I consider being a Carer a career?

Am I lonely?

Am I still in touch with friends?

When did I last go to the cinema?

When did I last see a play?

I kneel to bathe her feet.

She bends to stroke my hair.

Appendix 2- Picture of Caring

The local picture

Population: 300,123

23,395 provide unpaid care

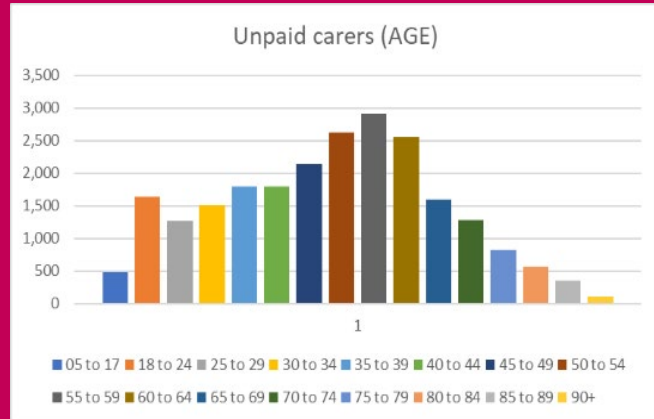
7209 provide 9 hours or less

3043 provide 10-19 hours

2345 provide 20-34 hours

3129 provide 35-49 hours

7667 provide 50+ hours



Newcastle GP Patient Survey: Carers



CONTACT



26%

of carers ordered repeat prescriptions online

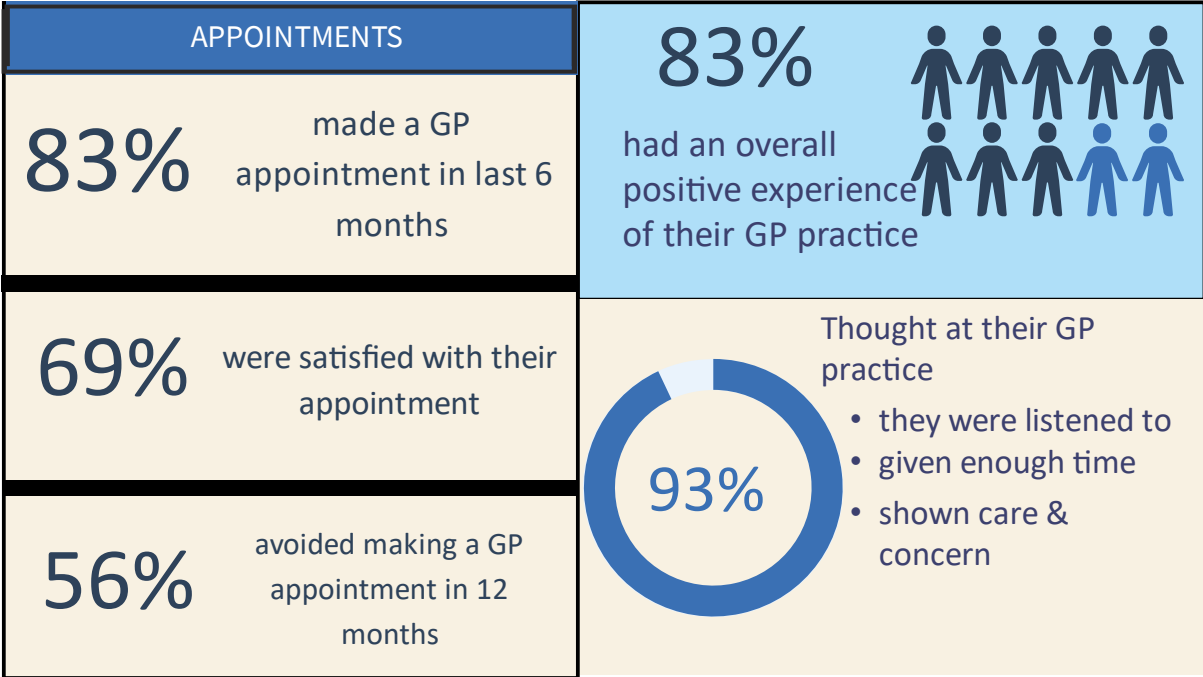


14%

of carers booked appointments online

54%

of carers said it was easy to get in touch by phone



Appendix 3

Conversation with a carer: Semi structured questions

- Tell us a little about you and your caring role.
- How long did it take you to realise that you were a carer?
- Why do you think that was?
- What would have helped?
- What does it mean to be recognised as a carer?
- What works well for you in your caring role?
- Where do you think we as a city need to make improvements/take actions to support carers like you?

Appendix 4 – Table Exercise 1

How do you identify and engage with carers?

- Build relationships with other organisations to get referrals.
- Make referral process as easy as possible.
- Face to face conversations
- Collaborative working
- Link with Carers Lead
- Attend general 'engagement' events.
- Safeguarding - always ask about caring relationships – prompts on tools and paperwork – personalised conversation to ensure carers are identified and involved.
- Signposting at times of crisis
- Share information in a range of formats -online, social media etc.
- (We have a) Monthly support group for students who are carers – coming to college whilst having caring responsibilities.
- Identify needs for neuro-divergent parent carers.
- Provide emotional and practical support for carers – 24hr helpline and local resources to do home visits – face to face contact and signpost to services.
- Ask questions – specific to task/support they provide others as opposed to 'are you a carer'.
- Talking Point – online community facilitated by trained people – peer support, information readily available (Dementia Support Forum).
- Carers passport looks at measures/support which could be put in place to support access to higher education – making people aware of this , remove barriers to access this support.
- Sister-in-law identified (me as a carer) as I was not aware – vaccine during COVID.
- No formal process that (I'm) aware of
- Word of mouth
- Incentives to register e.g., max card.
- Faith groups in communities
- Coffee mornings/face to face opportunities – promote via specialist sessions/services/networking events, online/social media e.g., pass it on parents, sharing information, hints and tips.
- Newsletters – professionals/parents and partner organisations

- Social care, people involved with diagnosis - helping build awareness.
- NHS
 - people accessing services record carers who are supporting.
 - Policies support carers (but) are they applied.
 - Innovative projects
 - GP (importance of professionals identifying)
 - When patients arrive/admitted into hospital

- Employers – identifying people in caring roles.
- Carer recognition tools
- (When they) Act on behalf of cared for person e.g., power of attorney.
- Identification through benefits (applying)
- Open conversations (may self-identify)
- Asking the right questions
- Self-identification
- Care Planning (social services)
- Family and friends
- (Awareness)Sessions at Schools/High Schools/Colleges and universities
- Community events
- Churches and religious/faith establishments
- Family hubs
- Newcastle Carers
 - Massage
 - Counselling
 - Email invite to register with Newcastle Carers
 - Outreach important.
- Direct referral (to services and support)
- Referral via GP/Hospital
- Acknowledging caring role
- Inform friends and links (to information/support).
- Importance of online links/information as potential numbers (of carers) are large.
- Carers direct payments
 - Dementia adventures
 - Respite Care
- Northumbria Uni – carers passports
- WAGS and Co – befriending via pets/dogs.

Appendix 5 – Table Exercise 2

Weaknesses/challenges

- GP referred to memory clinic – (I) was recognised (as a carer) and received support but not until diagnosis.
- Difficult as people (carers) think it's their responsibility and this is not explained/explored.
- Hard to self-identify but (you) accept label (of carer) to get support.
- Not able to leave the person you care for to take part in support/activity.
- Feel guilty for trying to apply for support especially when told not eligible.
- Multiple organisations offer elements of support.
- Lot of responsibility with Newcastle Carers
- Surprised that people don't know about Newcastle Carers (lack of knowledge)
- Proactive, not reactive – (carers) not getting into a crisis.
- Expectation of (being available) 9 – 5 which doesn't take into account
 - People who work.
 - GP appointment at 2pm is difficult.
 - Assumption is that carers are retired – not just about retired people.
- Postcode lottery
 - Volunteers, health services etc
- Respite care
- Funding
- The door is shut.
- Young carers – don't just work with young carers (especially) but also adults. It's a whole family approach.
- Signposting
 - can go round in circles.
 - can take months – so give up.
 - false sense of hope
- Organisations
 - Staff capacity
 - Annual leave etc
 - No continuity – should be able to work with someone else.
 - Services/organisations should have access to all information.

- Information incorrect e.g., care plan not up to date
- Training
 - Is training ongoing.
 - Is there even training.
 - Mandatory training, but also other training needs
- We don't share resources.
- Communication needs to improve.
- Staff need training and understanding about needs e.g., dementia.
- (Managing) Expectations
- Tailored support for individuals
- Carers are forced to be proactive.
- Carers don't know what they need.
- Don't want a badge (labelling)
- List of phone numbers didn't help as it was still hard to identify who to call/what they do.
- Carers often have to keep repeating their story.
 - Feel worn out/drained.
 - Need to conserve energy for the person you care for
 - Give up asking when its challenging to find what you need.
- Constant changes (in the system)
- 'out of hours care' for the cared for
- Lack of capacity and resource
- Long waiting times- adds to the crisis.
 - For GP's and for assessments
 - Adds to caring responsibilities.
- Resources/funding – short term funding/commissioning of services, staffing ration – support ad capacity of support staff – wellbeing.
- Impact of resources/funding on focus on engagement – conflict with forming relationships
- Barriers for small organisations to apply for funding.
- Training and awareness within organisations
- Barrier in larger organisations – small fish in a large pond
- Benefits/financial constraints, cost of living for carers/families.
- Bureaucracy/processes – makes access difficult along with language used.
- Online – unable to us/or have tech/costs.
 - In too many places

- Not one access route- navigating this is challenging e.g., search terms.
- Local authority needs to keep information relevant and up to date/different numbers of people in post/ people coming back to you (they don't)
- Consultation/survey fatigue
- 'Off the peg' (support) - needs to be personalised.
- Training – carer awareness for personnel – all to aid/access/build confidence in the workforce/approach/language – do you care for someone?
- (We) Add to the carers load rather than alleviating it.
- It's all words with no support.
- People with disabilities (and their carers) aren't always aware of direct payments.

Appendix 6 – Table Exercise 3

Opportunities

- Can we have NE carers, so it's more joined up. Having local branches , Durham, Newcastle, Gateshead makes it complicated for information sharing.
- Run support for carers and activities for the person at the same time.
- Offer opportunity to take a trusted person with you to an activity.
- Celebrating /recognising carers – accepting care as part of everyday life – we all need care at some time.
- One-stop shop (for all things carer).
- Instead of signposting – go through the steps with the carer - signposting can be great; however, (it can) also a 'go-away'.
- Ask/Tell how long it will take/follow up/timescales = builds confidence (communication)
- Inclusive community hubs/events → carers involved, agencies, everyone!
- They would identify.
- Collaboration between organisations
- Advertisement – visual prompts everywhere e.g., metro, centres etc
- sharing resources – joined up approach e.g., community hubs play a good part in this.
- As a carer you question is it worth the time filling in the paperwork; don't have time to research or look at websites.
- Make referrals and processes easier.
- Have prompts.
- Information needed but why so many surveys – can't they all feed in together – constantly asking but never seeing change.
- Time is a challenge – can't all the questions be put into one (survey)
- Recruitment issues – vacancies that are difficult to fill in care work.
- Adult social care questionnaire – repetitive questions – can this be better.
- Why are the demographics so important?
- Caring needs to be everyone's business.
- Training and education - Conversations and awareness between people

- Concerns around duplicating work – communication needed.
- ‘Who am I’ document for carers to stop duplication.
- A central point to share information e.g., an app (or similar) so you can see that progress is happening – where things are in relation to enquiries and assessments etc and practical information such as when a worker is on holiday.
- Targeting places where carers would visit on a daily basis – pharmacy, community cafes etc.
- Word of mouth is quite powerful.
 - Getting into communities so carers can access information and support in a timely manner – plant the seed so they know where to go at the right time.
 - Range of formats of up-to-date information – carers don’t have the time to chase information.
- Waiting lists - need information etc (about where you are in the system)
- More volunteers that might be unpaid carers who could be part of the solution – information, advice, awareness using the skills of people who have cared- Give something back – have a role.
- Target big employers/contacts, break down stigma, feels stronger issue for men. Recognise and have practices and procedures too. Perception of who’s role – ‘Carer aware’.
- Information in all places – bus stops etc
- Financial advice is a huge challenge – transition as carer – person in care still having to manage other tasks – left in limbo – cliff edge.
- IT technology – helpful but challenge – especially if not online – buddy/help (needed)
- Ensure staff are communicated with/know what’s available/who is a carer/caring (education, comms, training)
- Language – plain English- real examples (animations – young carers)
- Supported = face to face, more human, not digitalised- need trust
- The word/language ‘carer’ – break it down, explain.
- Use examples, associations – people can relate.
- Carers have to be involved – user led, not just box ticking – carers are the professionals, peer mentors, lived experience – ‘nothing about us without us.’

- Information sharing between organisations – still GDPR data protection could be a weakness – what the individual wants to share.
- Simple referral forms – some forms ask a lot of irrelevant things – needs to be clear why the information is being asked for and what it's going to be used for – can ask what else is needed at a later date – streamlining.
- Online/apps – need to be operated by a human and chats/support e.g., Facebook groups need to be moderated well!
- Education
- Health care plan – identify (14) year 9 – a review here?
- Planning for adulthood
- Health and social care
 - At diagnosis
 - All age
- Recruitment (Employment)
 - 'we welcome applications from carers.
- Hospital/ ward packs – keep offering (including outpatients)
- Carer navigators in NHS/Social Care teams and departments
- ABCD – assessed/grass roots.
- Fear of someone with a () and taking over
- Acceptance of cared for in carer getting support.
- Limited without power of attorney
- Being able to be open (honest)
- Need to make it easier.
- Greater marketing – normalising
- Challenges around filling out forms – need sensibility.
- Accessibility of support/timings
- Employees awareness (education)
- Interpretation of Carers Leave Act.
- General social awareness
- Social opportunities /importance of social networks
- Carer identification tools
- Different cultures understanding of carers.
- Identification of carers
- Consistent carer recognition 'tool'
- Only tell the story once
- Sharing of information
- Identification through employment

- Data sharing- privacy notes
- Awareness in society/training
- Understand why (we are) asking the question.
- The so what – can support be offered (expectations).
- Schools/health

Appendix 7 – Table Exercise 4

Threats

- Worry/lack of confidence when going to a new service for the first time is off putting.
- Finances/availability – assessment/eligible/not eligible
- Data protection/information sharing.
- We'll lose carers because they'll lose hope, or the door is closed – leads to not bothering to ask.
- Resources
- This takes time.
- Needs organisations to invest in time and training and value carer awareness.
- Capacity
- Marginalised (communities of carers)
- Stigma
- Isolation
- Lack of understanding /caring role
- Lack of knowledge of where to signpost.
- Squabbling about information sharing agreements – not getting there

Appendix 8 – Table exercise

What could we do going forwards? (quick wins)

- Face to face (is a must)
- Ask the question, not make assumptions. Many occasions and not asked (system one) and only seen as a family member.
- Information
- As a carer if went back to role would ask
- Carers champion – low profile. Needs to be an essential role.

Appendix 9 – Poem - The Washing Machine – Catherine Graham

The Washing Machine

She dislikes the sound of the washing machine
so I sing as it starts to spin, willing it to stop
before she calls for me from the bathroom.

She used to love hanging the washing out,
proud to peg 'the whitest sheets in the street'
and watch them as they billowed on the line.

Sometimes, they'd be bone dry but she'd
leave them out, on show to Mrs. Ridley.
I remember how Mrs. Ridley and my mother

would stand, arms folded, like bookends
in headscarves and slippers exchanging the latest
chinwag. I remember the pleasure Mam took

in folding the bedclothes with me, how
she'd do that little dance towards me until
our fingers met, her fingers gentle and plump.

'Where are you?' she shouts from the bathroom,
'I've sat here two hours!' It's been two minutes.

I hurry along the passage, still singing 'our' song.

Keeping her face to the wall, Mam joins in.

We sing our hearts out to *Delilah*,

each of us as lonely as the other.

Appendix 11 – Poem - Pantomime – Catherine Graham

Pantomime

If I were brave, I'd peel them off, but
she loves them, self-adhesive stickers with
pink rose patterns she pressed onto the tiles
two years ago. She likes to fix the curled
up corners as she sits on the shower stool.
She's my Mam when she asks if I'm ok
as shampoo splashes my eye. I could cry
and get away with it, pretend it was just
the silly shampoo. Clouds of baby talc fill
the cubicle; my fault, I forgot to keep it
out of reach. White dust settles on our hair
and eyelashes as another sticker breaks free
of the tiles. Mam emerges from the haze
like The Snow Queen in our every morning
pantomime. I take the liberty of laughing.

Appendix 12 - Feedback

What was the best part of today?	Why was this?	What would you like to see happen next?
Chatting to other professionals - realising we are all working towards the same goals with similar values	Sometimes it can feel difficult to get the funding and resources needed to support carers and it was good to hear what is going on across the city	Raise awareness with frontline staff on where to signpost carers. Removal of some of the existing barriers to carers and cared for getting support
Conversations with carers and carer poetry. Time to listen and discuss	Hearing carer views in an open and honest way	More people engaged that aren't already carer aware. More action by organisations. What changes can they make?
The carer input (conversations and poetry)	Always better to hear from people with lived experience. Very powerful	Multi-agency support and enthusiasm for the city's carers strategy
The discussion	Engaging with others was really great.	A joined-up action plan
Blend of people and agencies	Ability to hear from people with lives experience and beyond	Further opportunities to network
Speakers and array of information available	Very useful	Same layout , brilliant venue
Being able to talk about issues	Nobody else wants to know	evidence of change
Listening to carers	We need to hear carers experiences and learn	Incorporate carers views into future planning

What was the best part of today?	Why was this?	What would you like to see happen next?
All of it, especially discussions on the table	Interesting, relaxing atmosphere, no pressure to speak out loud, good facilitators	Positive action or at least acknowledgment about the things raised- many of the things discussed I have heard again and again at various network meetings and it is so good to see progress but more still needs to be done
The table conversations. I learnt a lot	Great to hear from different organisations and what they do. Have made some useful contacts	I would be very interested in any follow up events and also the neighbourhood meetings
the realisation that there is a lot of support available	Didn't appreciate all the different agencies	everyone to be aware of carer support
The sharing of ideas, views and energy of commitment	Often don't get the chance to hear people's direct views	Carer's view brought together to make real action
Tabletop exercises of exploring improvements and solutions	Aware of the issues that we need to move forward on in partnership with carers and those cared for	High level priorities
the realisation that there is a lot of support available	Didn't appreciate all the different agencies	everyone to be aware of carer support
What was the best part of today?	Why was this?	What would you like to see happen next?

Meeting people from other strata of the carer's world	Hearing other people's experiences. Being able to pass on good ideas. Being able to praise where things have gone well	Opportunity as a carer to be involved with planning/developing things.
The 'conversations with' a carer	I enjoyed their honesty, straight talking and willingness to share.	That change happens quickly and staff receive appropriate training.
Carers' stories & poems - real-life experiences to bring the (great) wider discussion to life.	As above.	The day was ran really well - thanks . Brilliant discussion & involvement from everyone. I'd like to see the feedback brought together in a report & recommendations.
Hearing from carers, their story. Also hearing that NCC are planning co-production	This ethos is important. Examples are important to get message across	Using info discussed, summary of work & moving forward as quickly as possible
The group discussions, the guest speakers	The group discussions were very interesting and informative. Found out about different services to support carers in Newcastle	The feedback taken on board and changes happening. Also, more carers participating in the next conference , advertise the event better - posters in family hubs, community centres, charities, GPs. Make it clear that expenses will be paid for carers and lunch will be provided.
Listening to carers and their roles	Because it was real	More funding and not always relying on the voluntary sector

What was the best part of today?	Why was this?	What would you like to see happen next?
Being listened to	I felt that most of the staff I spoke to were genuinely interested in what I had to say	Turning this learning into service design experiments
Therapeutic talking to like-minded people about some of the issues I have been dealing with	Not enough people understand what I have been through.	Opportunities to volunteer or assist in future to use the skills I have developed.
The activities brought up some great conversations, it was great hearing from the others on my table	Everyone had very different experiences and perspectives to offer	Future events to update on the work being done to support carers. A separate event for young carers would be helpful with organisations and workers who specifically support young people
Talking directly with carers	Great to get feedback directly from carers about their real-life experiences and what it's like on the other side of receiving services.	Looking forward to seeing the report with next steps.
It was interesting listening to other carers experiences sat on my table.	I had the opportunity to discuss my own experiences and for the first time consider whether I am a carer myself.	I would like more opportunities to connect with people and services on the community to improve how I am able to support others in my social prescribing work

What was the best part of today?	Why was this?	What would you like to see happen next?
Getting together with others	Few opportunities	Event write up with action plan names against tasks
Hearing about all the different services and from the carers themselves	I feel we all work separately, and things could be more joined up	More chances to catch up and share best practice, Network of professionals supporting carers in Newcastle
talking with carers have first-hand experience	this was really useful to hear from their perspective what does and doesn't work - for example I hadn't realised how many carers do not resonate with the word "carer"	<p>more support on HOW we make changes - I feel a lot of this discussion talked about things that we would like to see change, without any real discussion on how we can each begin to implement changes / drive change</p> <p>I also think if there's another meeting there should be more info re the services available - what services support carers and the person being cared for, what support do they offer, how can carers engage (e.g., referral form process) - as a professional this would support me when discussing support options with my patients</p>
Networking. Information sharing. Giving opinion	People now know we exist. Able to give input	Action, not words. I would like the role of carers challenged by campaigning for full payment for carers (caring) and carers name change

What was the best part of today?	Why was this?	What would you like to see happen next?
The table talks/exercises	The table was quite diverse so lots of different viewpoints, expertise and passion to be shared. A chance for collaborative sharing	A report to be shared of today listing a timetable of proposed actions
Meeting people and hearing other people's views	No time to meet other people	Words put into actions
Hearing so much info. I was completely unaware of contacts etc. Being able to mix with professionals and other carers	I would never have had the opportunity otherwise	More of the same please. Similar or drop-in sessions local to me. The Nunsmoor Centre next to Nunsmoor Park would be a great local venue. Lots of community things there
Hearing about Newcastle Carers	I didn't know much about them	Another conference as missed everything from the morning
Hearing from carers.	Learning from personal experience	More liaisons with people in caring roles. More funding!

What was the best part of today?	Why was this?	What would you like to see happen next?
<p>To meet a varied group and find that there are common areas of concern amongst carers. Good to see positive steps that will help carers in the future to find relevant services. Still need to work on social services network map as I am still unclear how the various departments are connected. Still failed to get blue badge after two attempts and one appeal</p>	<p>As a carer there is a great sense of isolation and there is no longer time to research all the websites to find the answers. Good to see the enthusiasm to improve the status quo</p>	<p>A network map and contact details to provide access to the social services team</p>
<p>To discuss the needs and potential outcomes for carers and to see how much they are considered with so many organisations wanting to help and improve the services and how the services should/could be delivered</p>	<p>it meets my need to improve the lives of carers and my passion to make life easier for them</p>	<p>A review and for carers to be given opportunities to feed into services and take the lead on services going forwards</p>

What was the best part of today?	Why was this?	What would you like to see happen next?
Connecting with carers and hearing first-hand what they need, what could be better and what's working well. Crucial to hear it directly from carers and be led by them	inspires me to do more and continue to develop carer support and identification	Feedback from today with some clear actions about what needs to happen next