

Support for Carers



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Executive Summary

Introduction

In February 2014 Healthwatch Staffordshire had been invited by the Staffordshire Carers Partnership to lead on the engagement, insight and co-production task and finish group as part of the large scale review of the outcomes in the Strategy for Carersⁱ (2011-2016).

This executive summary provides a brief overview of the approach, findings and recommendations of that study. The findings align very closely to those presented in the Interim Report submitted to the Staffordshire Carers Partnership in May 2014. However, what differs is the volume of views secured which helps to emphasise the key themes identified throughout this study.

Methodology

The methodology employed for this study has focussed predominantly on establishing contact with carers by applying a multi-methodological and harmonised framework to ensure wide participation. As a result of applying this flexible methodology, Healthwatch Staffordshire engaged with 224 carers and 19 professional organisations. A breakdown of responses is presented in the table below:

Methodology	Response rate
Focus Groups	86 People (7 groups)
One-to-Ones	104
Telephone/Online	32
Professionals	19
Case Studies	2
Radio Talk Show	1
TOTAL	224 Carers + 19 Professionals

In addition to this, we gathered 115 comments related to the Carers Hub Toolkit, and also analysed information collected by Staffordshire County Council into seventeen young carers to supplement the main findings related to adult carers.

Main findings

The main findings of this investigation into carers explores a number of interesting themes which by and large mirror those extracted from research undertaken by both the St Giles Hospice and the Dove Service.

The common themes emerging from the various strands of research undertaken by Healthwatch Staffordshire can be broadly summarised as follows:

- Carers feel excluded by clinical specialists and as a result they feel undervalued.
- A lack of communication between carer organisations leads to a lack of coordination.
- The absence of relevant information results in a healthcare industry which is difficult to navigate. Better signposting and a single point of contact is required.
- There is an extensive need for financial support – predominantly because carers have to sacrifice work and find applying for benefits difficult.
- More employers need to acknowledge the role of carers, especially given that carers need to juggle both work and caring responsibilities.
- The transition from child to adult carer services, and from caring to bereavement, is weak and requires better management.
- Support groups are valued but there ought to be greater flexibility in opening hours.

- A lack of support for incontinence is a significant area of concern, especially as it affects so many people.
- Carers acknowledge a lack of emergency planning support, as well as the need for emergency care plans.
- More robust and flexible carer's assessments would be welcome.
- Recruitment of personal assistants can be complex, particularly when there are trust issues.
- GPs need to acknowledge the issues faced by carers.
- Carers find it difficult to enjoy a life outside of caring.
- Carers have difficulties in getting GP appointments that are convenient for both them and the cared for person.

In addition, whilst many young carers could not remember their assessments, none of those surveyed were concerned about being reassessed. There was also significant concern with the support that young people had within schools which tended to be inconsistent. This was primarily related to a lack of communication and awareness that they were carers.

We also made a number of significant findings in relation to young carers. The first point that stands out, and is a key consideration for any future work with young carers, is how to effectively engage with a varied cohort of young people when many have a perceived fear of talking about their responsibilities with officials. This represents a significant problem because services are unlikely to improve without in-depth feedback from young carers.

A carer's assessment presents young carers with an almost perfect opportunity to inform social services about the things that could make caring easier for them. However, this research highlighted how many young carers could not

even remember the last time they had an assessment.

Young carers spend a considerable part of the day in schools and therefore schools present an ideal opportunity to identify the level of support an individual might need. However, at the moment very few individuals actually received any meaningful support and it is suspected that there is a sizeable cohort that are hidden carers.

Knowing that young people are carers helps doctors to understand their health needs and may even give them better access to GP services. Yet this research highlighted that not everyone knew of their caring responsibilities or offered any meaningful support when they did.

Support groups provide a valuable mechanism for engaging with young carers regarding their fears, worries or concerns.

The main findings also concluded that there was significant alignment between the messages given by both carers and professional organisations. For example, both parties agreed that services are fragmented, support groups are valued and that carers feel tired and fatigued. There is also agreement that carers don't value their own needs and that carers can be reluctant to ask for help.

Overall, Healthwatch Staffordshire could identify three priorities emerging for carers:

1. *Respite care provision* – as most carers need a break from their caring role
2. *Finance* – information on what financial support carers are entitled to receive and support to fill out forms. Many carers felt that if it wasn't for support groups they would not have realised their entitlements to specific benefits.

3. *Information, advice and support for carers own health* – currently carers have to find information out themselves.

In terms of next steps it is important to understand how carers should be involved in the design and delivery of services so that providers and commissioners can better meet their needs. This requires the establishment of an ongoing mechanism for young carers, adult carers and professionals so that they can benefit from co-production opportunities.

Recommendations

1. Greater collaboration is required between the NHS, Social Care, and community and voluntary organisations so that they can provide a joined up approach to information sharing
2. All carers should be assessed regularly using a flexible but robust approach
3. A checklist should be given to all carers at the beginning of their journey as part of a comprehensive information and signposting pack.
4. A central hub should be created which gives carers flexible 24 hour access to information, advice and guidance
5. Carers should be given greater recognition for the role they perform
6. Greater transitional support is required between young and adult carers and throughout bereavement.
7. Greater flexibility and availability of GP appointments for carers
8. GPs should be monitored in respect of the support and signposting they offer to carers. This would require the production of a consistent framework of responsibilities.
9. Continence services and the speed at which those services react to needs across Staffordshire need to be improved
10. Co-production mechanism should be developed
11. Create an engagement model that encourages young carers to provide comments in a safe environment where they feel both comfortable and confident
12. Ensure that assessments for young carers are both formalised and regularly undertaken
13. Ensure schools are more proactive in identifying and supporting young carers with their responsibilities.
14. Ensure young carers are supported to talk to their GPs about their roles and their needs as carers.
15. Encourage young carers to seek support from relevant agencies.

Introduction

Overview

Taken as a whole group, Carers provide a valuable contribution to society and remain a recognised key priority for the Department of Health (DH) and the Care Quality Commission (CQC). Carers UK calculates that the care supplied by friends and family members to ill, frail or disabled relatives is valued at £119 billion a yearⁱⁱ. This has risen by more than a third since the 2007 estimate of £87 billion. It is also estimated that each carer saves the economy £18,473 a year. Applying this costing to Staffordshire suggests that carers' contribution is worth £1.825 billion per year.

As a result of the role performed by Healthwatch Staffordshire, we were invited by the Staffordshire Carers Partnership to lead on the engagement, insight and co-production task and finish group as part of the large scale review of the outcomes in the Strategy for Carersⁱⁱⁱ (2011-2016).

This project harvested information from various strands of primary research, to inform the review of the twenty-seven service specific outcomes currently contained in the Strategy for Carers. The final output of the study is this report and a presentation to the Staffordshire Carers Partnership Governance and Strategic Direction Group on the findings and recommendations.

Healthwatch Staffordshire

Healthwatch Staffordshire, which is delivered by Engaging Communities (ECS) is the new, independent consumer champion for health and social care for local residents. The role of Healthwatch Staffordshire is to argue for the consumer interests of those using health and social care services across the country and to give local people an opportunity to speak out about their concerns and health care priorities.

Backed by Healthwatch England, we have statutory powers to listen, act, challenge and feedback, improving local services and promoting excellence throughout NHS and social care services.

In view of this remit, we were therefore ideally positioned to deliver this project on behalf of the partnership. Support for Carers also represents one of three key priorities for Healthwatch Staffordshire for the period 2013-14.

Definition of carers

There does not currently exist a single universally agreed definition of a carer. However, for the benefit of this report we will use the definition stated in the document *Commissioning for Carers* [2009] developed jointly by a number of carers and commissioning organisations including the Association of Directors of Adult Social Services [ADASS] and the Improvement and Development Agency:

"A carer spends a significant proportion of their time providing unpaid support to a family member, partner or friend who is ill, frail, disabled, or has mental health or substance misuse problems."

A young carer is defined as a carer below the age of 18.

Review of literature and data

The county of Staffordshire is characterised as being composed of a diverse range of people and places. It covers a range of rural and urban settings and has a population of around 1,097,500^{iv} (which includes a Stoke on Trent population of 249,000) representing a growth of just under 5% from 2001. Approximately 4.3% of Staffordshire's population belong to an

ethnic minority group, the biggest subgroup being Asian/Asian British (2.4%).

In common with other areas, Staffordshire has an ageing population, with over 25% of people above the age of 60, which is considerably higher than the England average of 22%. In fact, the mean age in Staffordshire is 41, whereas across England it is 39. A lack of adult physical activity and adult obesity are among the most prominent health problems in Staffordshire.

Around 12% of the population of Staffordshire undertake unpaid care. Nearly a quarter (23.7%) of these unpaid carers are above the age of 65, but the vast majority are in the 50-64 age group (38.3%). More surprisingly however, is that there are just over 1,500 unpaid carers under the age of 15, which presents an interesting challenge.

Caring is not only the responsibility of the old. In 2013, the *Children's and Young Peoples Survey* showed that 21% of young people looked after someone in the family who had an illness or disability. Similarly, the Children's Society report *Hidden from View* [2013] identified that young people are one and a half times more likely to be from a BME group.

The Carers UK National Carers Survey (*The State of Caring, 2013*) found almost a third of those caring for 35+ hours a week receive no practical support with caring, and that nearly a half of carers (44%) had been in debt as a result of their caring responsibilities. More worryingly, 92% of carers believed that their mental health had been affected by their obligations as a carer.

The report highlighted five challenges to improve carer's lives (which accurately reflects the findings from this study):

1. Ensure access to support and information.

2. Deliver services and workplaces that support carers to juggle work and care.
3. Act urgently to prevent carers' financial hardship.
4. Ensure carers are able to achieve the best possible health outcomes possible.
5. Deliver high quality care and improve the interface between health and social care services.

Across Staffordshire, the recent *Carers Survey* (2012-13), covering nearly 500 respondents made numerous observations. For example, it found that 12% of carers did not receive any support services in the last 12 months and only 8% had tapped into support, which offered a break from caring for 24 hours or more.

The survey also found that 60% of carers had accessed information and advice to support them in their caring role in the last 12 months. In addition, 77% of carers had been caring for someone for five years or more despite 19% having a long standing illness.

Dementia is becoming an increasingly significant issue in the workplace as more people are combining work and caring for older, sick or disabled parents, and loved ones (Carers UK^v, 2014).

Within the UK, the Alzheimer's Society estimates that there are 800,000 people with dementia. Unpaid carers provide a major part of the support to people with dementia and there are already an estimated 670,000 people in the UK acting as primary carers for relatives and friends with the condition. The survey made the following key findings (which again align to the findings of this study):

- Clearer, more accessible information on dementia and how to get practical help

- A wider workplace response to people caring for loved ones with dementia
- Employers to play a key role in signposting carers in their workplace to sources of information and help with dementia
- Care and support services to be accessible, available and appropriate for people with dementia. Including specialist help when required.

The Dementia Action Alliance has put together a National Dementia Declaration supported by people with dementia and their family carers which has described seven outcomes they would like to see in their lives. These are:

1. I have personal choice and control or influence over decisions about me.
2. I know that services are designed around me and my needs
3. I have support that helps me live my life
4. I have the knowledge and know-how to get what I need
5. I live in an enabling and supportive environment where I feel valued and understood
6. I have a sense of belonging and of being a valued part of family, community and civic life
7. I know there is research going on which delivers a better life for me now and hope for the future

However, based on the findings of this detailed investigation into carers, various outcomes are still not being met. For example, there are many carers that lack the support that they need. There are also a significant proportion of carers that don't have relevant information available about the range of accessible benefits, or even where to get information about benefits. There is therefore a strong need to understand - from the perspective of the carer - how their needs can be better met. This report will hopefully

provide the momentum for addressing shortfalls in the carer marketplace.

Methodology and Approach

Carers and carer organisations have a vital role in influencing how local services are improved and delivered. In fact, the Health and Social Care Act (2012) serves to strengthen the voice of the public by welcoming all sources of feedback as a means through which to assess the quality of services. With this in mind, the methodology used for this study focussed predominantly on establishing contact with carers through a multi-methodological and harmonised framework. This was initially proposed as a way to ensure wide participation with hard-to-reach groups, as well as increasing the depth of information accumulated.

This investigation into carers had the ultimate aim of reviewing the twenty-seven service specific outcomes contained in the Strategy for Carers to explore whether they were still appropriate or required reshaping. The findings from the consultation exercise were aligned to the individual outcomes to provide a rich picture of carer views (see Appendix 6).

To kick start the process, a meeting was arranged with a small (non-representative) group of carers and carer organisations at Healthwatch Staffordshire to discuss a viable approach to gathering evidence to inform this study. At this meeting it was concluded that surveys would be somewhat restrictive and counter-productive given that carers were constantly bombarded with questionnaires throughout the year. Hence, alternative methodologies and approaches would need to be utilised – particularly as the nature of caring and carers makes it challenging to accumulate viewpoints in a consistent and methodical way.

In view of the fact that we were reviewing twenty seven outcomes, it proved difficult to develop a single methodology that would cover all the outcomes in a short, sharp workable survey. Hence, Healthwatch Staffordshire agreed to develop a qualitative approach that would seek their views on key areas of service provision, which we would then analyse and insert into the appropriate outcomes to assess their continuing viability.

Healthwatch Staffordshire also applied Conversation Staffordshire, a methodology designed to facilitate a two-way conversation between local carers and the organisations responsible for their services.

As a result of applying this flexible methodology, Healthwatch Staffordshire engaged with over 224 carers and 19 professional organisations. The following table presents the breakdown of responses for each methodology:

Methodology	Response rate
Focus Groups	86 People (7 groups)
One-to-Ones	104
Telephone/Online	32
Professionals	19
Case Studies	2
Radio Talk Show	1
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In addition to this, we gathered 115 comments related to the Carers Hub Toolkit, and also analysed information collected by Staffordshire County Council into seventeen young carers to supplement the main findings related to adult carers.

Focus Groups

The focus groups were delivered by employing a modified version of the Carers Hub Toolkit to extract useful material via an informed discussion. Following this exercise,

Healthwatch Staffordshire then undertook to map the findings to the twenty-seven service specific outcomes contained in the carer's strategy. The discussions were supported by the following five expansive question areas (see Appendix 2):

1. Describe how the local services support you in your role as a carer using only two words (one negative and the other positive).
2. Which support services do you currently use and what are your opinions on those services? Are there services which you wish to use which are not available locally, or which you are not eligible to use?
3. What are your specific needs as a carer and how do existing services meet those needs?
4. What should be the top three priorities for supporting carers and why?
5. Using the carer's hub toolkit, describe what each of the interventions/outcomes means to you?

The focus groups were based primarily on convenience sampling. However, every effort was made to ensure that each focus group contained as wide a group of cohorts as possible.

Following each focus group, the 'big ideas' or 'themes' discussed were summarised including any observations such as language, tone, and differences of opinion. This facilitated a deeper understanding of the topics.

The organisations that supported ECS in the delivery of the focus groups and drop-in sessions require a special mention and included:

- Crossroads
- Douglas Macmillan Hospice

- Katherine House Hospice
- Oakedene Day Centre
- North Staffs Carers Association
- Greyfriars Therapy Centre
- Dementia Support Group Blythe Bridge
- South Staffs Carers Association
- Approach
- MASE

One to Ones

To supplement the information coming out of the focus groups, a number of one to one meetings (104) were held with carers to discuss their views. These discussions were guided by a set of pre-set questions to help extract focussed information (see Appendix 3). The specific questions were:

1. What financial support do you currently receive, and what are your experiences of receiving financial support? What additional financial support do you think you might need?
2. Have you received any support to enjoy a life outside of caring, and what were your experiences? What other support might you need to enjoy a life outside of caring?
3. Do you feel supported and valued in your role as an expert care partner by service professionals? If not, what would help you feel supported and valued?
4. Have you received any support for your physical or mental wellbeing, and what has been your experience of accessing this support? What additional physical or mental health support would you like to have?
5. What would be your top three priorities for supporting carers and why?

These one to ones were undertaken across a wide variety of venues and with the continued

support of a number of carer stakeholder groups.

Radio Talk Show

We tried to apply an innovative approach to collecting information through the use of a radio talk show. This allowed us to target a wide sample of listeners to stimulate a debate around local carer services. The radio station used was Six Towns Radio.

Case study

The rationale for employing a case study approach was to provide a detailed appreciation of the journey that carers go through. Healthwatch Staffordshire produced a detailed framework for the creation of this case study to allow it to flow like a story (see Appendix 1). The prompts used to create this case study were as follows:

1. Describe how you started on your journey as a carer?
2. At what point on this journey did you associate yourself to being a carer?
3. What were your experiences of trying to use the carer support services (what worked well and what didn't?)
4. What gaps are there in the support services available for carers?

In total two anonymised case studies were produced and we are extremely grateful to the participants for their contribution.

The engagement provided a useful avenue for accumulating carer stories which allowed us to appreciate a specific aspect of their caring role. These stories were collected with sensitivity and guaranteed confidentially in an informal setting. We did not set out with the intention of posing a set of rigid questions to participants, instead aiming to openly stimulate a natural and casual conversation.

Telephone interviews

It was promptly recognised during the project planning phase that there could be an issue with getting carers to attend either a focus group or one-to-one session due to their commitments as carers. Therefore Healthwatch Staffordshire organised a number of short 15 minute telephone interviews with carers. Recruitment was initiated through a promotional campaign asking carers to contact us through the Healthwatch Freephone telephone number as well as via carer organisations. Areas that were covered during the investigation included (see Appendix 4):

1. What are the major barriers or hurdles that you have experienced in your caring role?
2. What support would you like to have as a carer?
3. What are your experiences of using support services as part of your role as a carer?
4. What should be the top three priorities for supporting carers and why?

In total we secured 32 Online/telephone based responses.

Carers Hub Toolkit

The Carers Hub Toolkit for Commissioners (Carers Trust), have produced a toolkit in consultation with Local Authorities and a clinical commissioning group. This toolkit was used to shape the consultation with carers and the third sector to provide a snapshot of carer's services in Staffordshire. The toolkit diagram shows the seventeen interventions and can be found in Appendix 7.

Desktop Research

A brief analysis of relevant information on carers was undertaken and incorporated in the report to provide the context for analysis.

Publicity Campaign

To promote this campaign, Healthwatch Staffordshire employed traditional forms of media ranging from local press and marketing through to community groups and events. We also used radio. In addition, we implemented a social media campaign through Twitter, Facebook and our own websites to encourage as many carers as possible to participate (see Appendix 5).

Quality Plan

ECS and Healthwatch Staffordshire has a responsibility to ensure that the evidence and insight it creates is of high quality and aligned to best practice across the industry. Research ultimately provides the evidence on which sound decisions should be made, which is why it is important to state up front how quality will be ensured throughout this project.

The Evidence & Insight Team underpins its research activities by applying the Market Research Society (MRS) Codes of Conduct, which allows us to demonstrate that we are credible, fair and transparent. ECS is now an MRS accredited Company Partner.

ECS and Healthwatch Staffordshire also adheres to a strict data protection policy which ensures that:

- Everyone handling and managing personal information internally understands that they are responsible for good data protection practices.
- There is someone with specific responsibility for data protection in the organisation.

- Staff who handle personal information are appropriately supervised and trained.
- Queries about handling personal information are promptly and courteously dealt with.
- The methods of handling personal information are regularly assessed and evaluated.
- Necessary steps are taken to ensure that personal data is kept secure at all times against unlawful loss or disclosure.

ECS also has firm guidelines in place for data storage, data retrieval, data security and data destruction. There is also a strict process in place should a data breach occur (which includes containment and recovery, assessment of ongoing risk, notification of breach, evaluation of the incident, and preparation of a formal response).

To further embed quality into the final report, an internal peer review process was initiated to ensure that the report was fit for purpose before submission.

Policy Analysis

The following section provides a brief summary of the key policies in relation to Social Care.

The Health and Social Care Act, 2012

The Health and Social Care Act (2012) puts clinicians at the centre of commissioning, encourages providers to innovate, empowers patients and gives a new focus to public health. The Act serves to strengthen the collective voice of patients by welcoming all sources of feedback as a means through which to assess the quality of their services.

The NHS Commissioning Board, Clinical Commissioning Groups, Monitor, and Health

and Wellbeing Boards all have duties with regards to the involvement of patients, carers and the public. Commissioning Groups will have to consult the public on their annual commissioning plans and involve them in any changes that affect patient services.

Children's and Families Act, 2014

The Act underpins wider reforms to ensure that children and young people can succeed, no matter what their background. The main provisions of the Act are:

- *Adoption and virtual school head*

This provision attempts to reduce the delay in adoption and promotes fostering and support for families.

- *Family justice system*

This provision attempts to reduce delays and ensures that children's best interests are at the heart of decision making.

- *Special Educational Needs (SEN)*

The SEN gives young people and their parent's greater control and choice in decisions and ensuring needs are properly met.

- *Childcare*

The Act supports wider reforms to increase the supply of high quality, affordable and available childcare and offering greater support and quality assurance so that it's easier for schools to offer wrap-around care.

- *Office of the Children's Commissioner (OCC)*

The Act grants more powers to the Children's Commissioner so that they can act as a strong advocate for children to protect their rights.

- *Shared parental leave and flexible working*

The government is committed to encouraging full involvement of both parents from the earliest stages of pregnancy, including by promoting a system of shared parental leave, and to extending the right to request flexible working to all employees.

Better Care Fund (BCF)

The BCF is a single pooled budget to support health and social care services to work more closely together in local areas.

The Care Act, 2014

The Care Act aims to reform the law relating to care and support for adults and the law relating to support for carers, to make provision about safeguarding adults from abuse or neglect, to make provision about care standards, to establish and make provision about Health Education England, to establish and make provision about the Health Research Authority, and for connected purposes.

Work and Families Act, 2006

This gives carers the right to request flexible working from their employer.

The Equality Act, 2010

Carers cannot be discriminated against because of their association to anybody who has one of the following characteristics: age, disability, gender reassignment, marital status, race, religion/belief, sex or sexual orientation.

Taken together, all the policies and acts mentioned above are there to ensure the rights of carers are protected as well as to state what Government would like statutory organisations to do for carers in England.

Other Acts

- *The Disabled Persons Act, 1986*

Section 8 says that consideration must be given as to whether a carer is able to continue to care

for that person when assessing a disabled person's needs.

- *The NHS and Community Care Act, 1990*

This requires councils to involve families and carers when making plans to assist adults who are vulnerable.

- *The Carers Act, 1995 & 2004; Carers and Disabled Children's Act, 2000*

Between them, these acts give carers the rights to have their needs assessed, and ensure authorities tell carers their entitlement to an assessment as well as offer vouchers for carer breaks.

Main Findings

The following section communicates the main findings which have been accumulated through the variety of methodologies employed. The key insights will then be brought together towards the end of the report to provide a summary of the themes, which will make it easier for the recommendations to be formulated. A summary of the findings have been aligned to the twenty-seven service specific outcomes and can be found in a table in Appendix 6.

The Carers Perspective

Carers are not being listened to

There was generally a wide distribution of actual (or perceived) obstacles that carers felt had impacted on their roles as carers. For example, one respondent had mentioned that they were neither included by hospital staff in the patients care plan, nor were they involved in joint discussions with mental health professionals when they visited the patient at home. This particular respondent had expressed their concern after the visit because

they had not been informed of the outcomes of the discussion with the patient and therefore felt isolated, unimportant, and 'out-of-the-loop'.

Another carer had remarked how there was:

"A lack of understanding from the Doctors surgery."

In fact, perhaps one of the greatest obstacles perceived by carers was ensuring that the right people understand and:

"...listen to carers"

As one respondent had stated:

"They need to know how it actually feels caring for someone."

There is a clear issue here around wider understanding throughout society in connection with the role that carers perform.

Changes are bad

Due to shift rotation and workforce renewal, it is often the case that different care workers are dispatched by agencies to support the patient over a period of time. This can lead to substantial apprehension and anxiety for some carers as highlighted by one respondent:

"He doesn't like it when we have different care workers as he doesn't recognise their face[s] and [becomes] distressed."

Due to this fact, and in an effort to circumvent any further distress, the carer had taken it upon herself to bathe, clean, and dress the patient herself, despite the fact that the carer was 75 years old. This additional responsibility had thwarted any opportunities for the carer to enjoy a life outside of caring.

Constant changes were viewed as a particular inconvenience for carers. A carer revealed that:

"When they change a service or location, it takes time for the patient to get used to it"

This can also be a significant hindrance for carers as they may have a longer journey to access services, ultimately leading to greater costs.

Having continuous care, and consistency in the people that deal with carers, was emphasised as being enormously important. Carers stressed that this would ensure their needs were being consistently met, and that the patient had an opportunity to develop a trusting relationship with the agency. As one carer highlighted:

"...it's frustrating and difficult to deal with two agencies and multiple carers. When a person has Alzheimers it's important to keep the number of carers to a minimum otherwise it's like a stranger coming through the door every day."

Another carer had stated that:

"I became a victim of crime as a result of different carers"

Lack of communication

Another issue pinpointed by a different carer, and associated with having several support workers, was the absence of communication, as:

"They don't seem to communicate with each other, so we constantly have to repeat ourselves"

This can sometimes lead to stress brought about by frustration.

Benefits and entitlements

A significant barrier faced by carers was linked to the distinct lack of benefits and entitlements support. Many carers reflected on the fact that they felt it was their 'duty' to care for a sick, ill or frail relative, and as a result many carers refused to submit applications for a carer's allowance.

Financial support was a specific area of concern mooted by carers. Given that the vast majority of carers endure a caring responsibility well into pensionable age, many experienced financial hardship as the benefits they were entitled to prior to state retirement age end up being withdrawn. In the words of one carer:

"Retirement should not be a barrier to receiving [a] carer's allowance"

Having consistent financial support was identified as a key priority for carers. Many were struggling to survive on low benefit allowances, and many examples were uncovered where carers were not aware of their entitlements. Being financially secure provided independence to carers, as well as helping to reduce stress and:

"Having a little bit extra so the worry is taken away"

Many of the carers surveyed received either a Disability Living Allowance (DLA) or a Carers Allowance (CA) to support them financially in their role as a carer. However, some slight variations existed. For example, one individual who received a weekly DLA was not entitled to a CA because they undertook part-time work.

Another individual was concerned because DLA had changed into Personal Independence Payments (PIP). This carer had obtained advice from the Citizens Advice Bureau (CAB) but remained uneasy about the changes.

Some carers would have valued receiving financial support so that they could undertake training and development. However, there were several respondents who pointed out that they were financially secure. Others hadn't obtained financial support because they were:

"...above the financial threshold"

Of those respondents that received no financial benefits, many had felt a requirement to take on part-time work to make ends meet.

Many carers had emphasised that they had not received any financial help because they were not supplied with sufficient information concerning their entitlements. For example, one carer had stated that:

"[I] have received no financial information or help in understanding what might be available"

Similarly, another respondent had mentioned:

"... [I received] no information or signposting at [the] time of diagnosis."

These respondent had to discover the information for themselves. In fact, this was a theme echoed by many carers as stated by a different carer:

"I found out from a friend rather than a professional, as no information was offered from anywhere else"

By and large, respondents valued the information acquired from support groups:

"Most information came from Approach. My daughter found the number for Approach and contacted them. Wasn't given info from anywhere else"

Although support groups were judged to be experienced at sharing information, there was still a perception that the information was inconsistent. For example:

"I received some information about financial support but not all"

In this case, the individual was unaware that attendance allowance was means tested or the level of entitlement that could be claimed. Other carers had only just discovered their entitlement to an Attendance allowance after a considerable time.

An additional area of distress was associated with the mounting costs of caring. For example, one carer had mentioned that his wife:

"...was receiving day care 1 day a week but costs [had] gone up to £50 per day"

And another had stated:

"Monies charged by all support agencies has increased"

This was a common theme acknowledged by many carers throughout the discussions.

Complex forms had prohibited many carers from claiming benefits. As a result, many had either not submitted their claims, or had their submissions rejected because of inaccuracies.

Finances were the biggest hurdles encountered by carers. Very often, the levels of respite offered was nowhere near to what was actually required. More often than not, carers had to fund any additional day/night sitting services out of their own pockets when their allocations ran out.

An area that came out quite strongly in the focus groups was access to funding and grants. Many had received grants of around £300 to fund breaks. Whilst this was extremely

welcome, many carers were out of pocket and felt that the money did not stretch far enough.

Many carers had learnt about grants through support groups like The Carers Association for South Staffordshire (CASS) or through carer's assessments, but generally felt there was limited information about what was available. In other words, unless someone told them about what was available it was unlikely that they would find out themselves due to the complexities associated with accessing the information. In a few isolated cases, long term carers (i.e. those that have been caring for 10 or more years) had often only recognised their financial entitlements many years after their carer journey had begun.

In some instances, carers were travelling long distances to get to support groups and articulated how the cost of travel had precluded them from accessing a wide range of services. In one illustration a carer had to regularly use a toll-road to get to a specialist residential college for her son. She expended a large sum of money travelling on the toll-road and learnt many years later that they were entitled to a Mobility Exemption Pass (MEP) permitting them to have free access. Regrettably, no one had mentioned this to them. In addition, the exemption information was buried deep on their website.

Carers were occasionally using social workers to help them fill out paperwork for benefits and entitlements. There was general agreement amongst some of the elderly carers that the paperwork was:

"Difficult to get your head around"

In fact, many felt that it was important to be careful when wording statements as:

"You can be very honest but it could jeopardise your own position by saying

something wrong – it's like they try to trip you up"

In other words, carers had to understand the sentiment behind a question, as well as contemplate how it might be interpreted by the person reading it. Carers also thought that claiming benefits was made out to be quite simple but in reality it was far from easy. In fact, many get disappointed by the lengthy and bureaucratic process, and one carer stated that:

"They try and harass you to the point that you give up"

In one instance when a carer had an application rejected they took the agency to a tribunal and lost the case. At the tribunal the carer stated that they were:

"Really nasty and it was a bad experience – they treat you like a criminal!"

When questioned further, the carer had stated that the agency wanted to take her husband's benefits off him even though he was having chemo-therapy every four weeks and was incapable of work. Another carer had experienced 18 months of trauma fighting for their rights. Even though the patient was being peg fed five times a day the funding agencies concluded that he wasn't eligible for any benefits. The point that one carer tried to make was that if you

"Played the game"

And were clever with the words used in the application form, you would probably be successful - even though you had very little right to that money.

Confusion about the different pots of money and the diverse places that they can be applied

from makes it a bewildering system when trying to access funding, particularly when thrown into caring roles.

As a consequence of not being able to claim benefits or entitlements, several carers were compelled to seek employment to cover their costs. In several cases, carers who were already in part-time employment had to increase the hours they worked to make ends meet, which adds significant stress.

Agencies like the Citizens Advice Bureau (CAB) were judged to be very helpful in general. However there were issues identified in making appointments to see advisors – especially at times which were convenient for the carer. In an example presented by a carer, the advisor requested a comprehensive breakdown of their finances before they offered to help. The carer had merely gone in to find out information about Attendance Allowance, but the CAB advisor stated they needed the information upfront because that was how they were funded.

In a separate example, a carer had used an organisation called Disability Solutions to access benefit advice and help to fill out forms. The carer had felt supported throughout the application process, which they welcomed.

Many carers would have appreciated knowing about the breadth of welfare benefits they could access but didn't know where to get advice on them. In addition, there are a number of support groups that are reluctant to provide advice on completing forms in case they jeopardise the claims.

At one of the focus groups, a number of carers discussed how there was often no sympathy for carers as they were regarded as "scroungers". This was despite the fact that it was the first time asking for a "hand-out" from the state. One carer had stated:

“We have contributed to the system all our life and just want what we are rightfully entitled too”

Interestingly, with benefit and financial advice it makes sense to provide an individual with a tailored service because everyone will have slightly different circumstances. In addition, over time, criteria and guidance can change significantly and this can make it very confusing when people are applying for benefits.

Many carers were not only unaware of their financial entitlements but also where to access information from. The information which is provided is frequently in jargon form and complex. The general feeling amongst carers regarding budgets was:

“If you don’t know where to go, you just go without”

Throughout the focus groups, one key theme emerged – that it was the elderly looking after the elderly. For example, a son/daughter in their 60’s would be looking after their parents who would be in their 80’s. Often, these carers would be unable to access the carers allowance due to restrictions based on accessing benefits into retirement age.

Most carers know about the Attendance Allowance and the fact that it goes to the person who needs attendance (individuals receiving the care rather than the carer). The problem with this is that the carer can sometimes miss out because the person receiving the care influences where it goes.

Another carer disclosed how she had to sell her home in order to find a property which was better suited to her circumstances. She contacted Staffordshire County Council who located a bungalow for her and her partner which she subsequently moved into. In total the carer received £115 per week, of which she had

to pay £70 rent per week, £15 council tax per week, and £15 for gas and electricity per week. She also had to pay an additional £4,000 up front in order to renovate the property before moving in. Currently the money from the sale of her house is paying the bills and the general upkeep of the property. However, she is concerned that if they don’t receive any financial support within the next 12 months, they will struggle due to fiscal hardship.

Information & signposting

Financial assistance was not the only area where support was deficient. Another respondent had revealed that they:

“...don’t know what help if any I am entitled too”

This is an important point underlined by respondents - predominantly because many carers are elderly and may be conditioned to accessing information using conventional methods. It may also demonstrate flaws in the carer market in terms of agencies and individuals tasked with providing support services to ‘hidden’ carers.

In this specific case, the carer had sought somebody to empathise with about her experience. However, she was uncertain about what was available or even where to go for that support. The absence of information on service availability was regarded as a substantial dilemma by carers who wanted to understand what was available. A carer had stated that one way to ensure this was to:

“[Have] greater visibility and publicity of what’s on offer”

More guidance and better signposting were suggested as options by carers to improve the situation. It was considered too time consuming and stressful because carers:

"Leave so many answer phone messages and [are] passed from pillar to post"

This not only causes distress to the carer but diverts attention away from the cared for person. One carer had divulged that:

"It can be very lonely and sometimes it's like fighting a losing battle, and [your] up against a brick wall"

Many of the commentaries collected from respondents relating to the support they would like to have as a carer were centred on information and advice. For example, one respondent had detailed how they would like:

"Information about what support is available around finance, respite, breaks and other general information"

This was predominantly because they had been given little information historically about what was already 'out there'. Similarly, another carer would also like to have had more information about what support they are entitled too particularly if:

"...I am entitled to any allowances as the main carer for my husband"

This particular individual had not been offered an assessment, nor been guided about where they might get more advice and information about assessments. This is possibly an indication of how reliant service providers are on the internet (and digital media in general) to get important messages out. However, the key failure point (in the view of many carers) has been a reluctance by agencies to comprehend how the vast majority of carers wish to be communicated with.

However, another carer had revealed that they had no familiarity with support services as they:

"...don't know what is available..."

In fact, this point was touched on by a few carers and appears to be a shared theme. Due to this absence of information, the respondents merely:

"...get on with it"

Support services were judged to be delivered infrequently, and this led to a perception that organisations were stretched and working at full capacity. Carers also viewed support services as having a wonderful opportunity to provide information to carers given that they were:

"In the right place at the right time"

Nevertheless, this opportunity was not being maximised or realised to its fullest potential.

Easy access to information is of primary importance to a great number of carers. Many for example, were not informed about their financial entitlements or where to access services.

One person stated that they would:

"...really appreciate the availability of somebody to talk to."

When probed further, this individual was conscious that there was a lot of information available in the marketplace, however, they wanted help to navigate through it and to make sense of it.

Another respondent had indicated that their daughter had a number of medical issues, but had to locate support for her daughter herself rather than through the medical community. This obviously took considerable time to research and could have led to a deterioration of the patient by the time they found the information they needed.

Furthermore a different carer stated that:

"I don't know what's available to me in terms of information... [I] don't like the lack of information or not being informed"

Many carers had revealed that the most useful information they had received about caring had been through volunteer run organisations (NAS). One respondent in particular had stated:

"[I] picked up loads of information at the GPs practice. It's a lot of information and I feel overwhelmed"

Throughout the discussions, many carers had stated that they wanted not only better information but also to make sure that everyone gets the same information and support.

Elderly carers were highlighted as experiencing significant issues with understanding information. One respondent had mentioned:

"Although I have been given a lot of information I feel swamped with it and can't take it all in"

This individual had highlighted a need for information to be explained more than once to ensure it was absorbed. This was due to a deteriorating memory and difficulties in contextualising the information.

Although the top three priorities for supporting carers differed between respondents, most carers highlighted information as an issue to varying degrees. Some respondents required information of what entitlements they could get (specifically focussed around finance), whereas others wanted more of a signposting function.

Information was difficult to access because it was widely scattered across different agencies. Many carers were often confused about where to procure information and would welcome the establishment of a central repository – a one stop shop – where they could be signposted to their intended destination.

It was not only important for the information to be made available in a wide variety of formats. Carers had also requested it to be presented in a clear and concise way to remove any ambiguity.

Many of the carers surveyed were elderly, or had very little spare time to spend absorbing and contextualising information. Therefore, presenting the information in plain English would be a considerable help to carers, particularly when they have to explain the information to the cared for person.

Many carers felt that there should be a central point of contact to ask for help any time of day. In fact, the lack of information is so severe that some carers were unaware of their entitlements to respite support. In a significant number of instances, carers only discovered information regarding benefits or entitlements through support groups and/or word of mouth many years later. In the words of one carer:

"You would think they would have found it easier to get the message out by now"

Carers are often thrown into a caring role and have little time or opportunity to search for information early on in their journey. GP surgeries are often the first port of call for most new carers but they are often confused about the wealth of information in surgeries which can be quite overwhelming for some people. One carer stated that:

“I don’t know what help and support was available until 18 months ago, even though I have been caring for my wife all these years”

Individuals are also not immediately aware that there is a directory of services¹ available online which can signpost them to various services. However, not every carer has access to the internet so they often have to rely on GPs, friends, and family to support them initially.

The local council was criticised as one focus group mentioned that they didn’t tell them that they were entitled to get a 25% council tax reduction if they met certain criteria (such as experiencing mental incapacities). Many carers generally felt that they had to ‘dig’ for the information themselves.

One carer felt that there was a lack of information relating to residential care, and as a result of his experience had learnt how to ‘fight’ with social services. The relative who he was caring for had to attend both GP and hospital appointments, but the doctors/medical staff at the GP and hospital both refused to share any information relating to the relative with the carer due to patient confidentiality, despite the carer having power of attorney. As a result, the carer became extremely frustrated and disenchanted with the system.

A concerned carer had highlighted an issue he had experienced with his wife who recently went into hospital. Since his wife’s condition was deteriorating, the Doctors asked the husband to fill out a red form because her quality of life was getting worse. The red form is often completed when doctors make the decision not to resuscitate a patient when their heart stops. The carer had signed the red form

because the clinical registrar began to talk about legal responsibilities. However, when the carer discussed the issue at a local support group they were informed of the fact that they could create a living will so that the carer had the final decision about whether or not to resuscitate a patient. This is an important example of how – due to a lack of information – the carer had temporarily given away authority to make a decision on whether his wife lived or died if her heart failed.

Those carers who had been in the system for a number of years felt that they benefited from the closer involvement of the Community Psychiatric Nurse, who were able to monitor the progression of dementia more closely, and could provide information (and support) to the carers as and when appropriate.

The current system is fragmented and is more medically oriented. There is an information pack given out at the point of diagnosis, but the information within it can be too overwhelming to receive in that format, especially without a person that can talk carers through what they need to know at that point in time, and what to defer until a later stage when it is more pertinent. Too much information in the wrong format at the wrong time may be disregarded altogether. One carer commented that the pack she received a few months ago from the Mental Health Trust included a lot of names of different organisations, but not enough information about them individually, to help her identify which ones may be useful to her. The carer mentioned that they would have liked someone to sit down with her and go through the pack and point out what might be relevant, given the specifics of her situation, and what to bear in mind for the future.

¹ www.staffordshirecarespurplepages.info

Generally medical clinicians are unable to point people in the right direction, and therefore information is picked up in an ad hoc way. For example, via neighbours and friends and sometimes from advice and support workers. Knowledge of the role of Social Services was very weak, and knowledge of their rights as a carer to be offered a carer's assessment was generally poor.

Only individuals who are outgoing and are happy to attend support groups are more likely to get the information they need, rather than those who find these outlets quite daunting.

Balancing work and caring

Carers frequently have to juggle work with challenging and stressful caring responsibilities. For example, a carer had disclosed that:

"Not having any support or respite, and trying to balance working full-time, was difficult"

Greater support to continue in employment was a significant issue for a number of carers. One individual had stated that:

"I don't qualify for carers allowance so I am penalised for trying to balance full-time work with [my] caring responsibility"

Linked to this was an expectation that:

"Employers should listen and support carers much more"

Employers can offer relief in many ways. For example, acknowledging the significant impact of caring on individuals, and by providing additional benefits that promote wellbeing so that carers can remain in work.

Carers also had an aspiration to be recognised as expert carers. Many felt that

"...the profile of carers needs to be raised."

It was viewed as important that employers continue to support carers by allowing them to take reasonable time off to support their caring responsibilities. This flexibility is not consistent amongst employers with some better than others. In one example a carer had to look after a sick partner and stated:

"When my partner had a funny turn my employer wouldn't pay me so I had to take unpaid carers leave."

This incident caused significant strain to the individual because they knew they had to both work to pay the bills, but also care for a sick relative. The individual was also reluctant to apply for any benefits or to ask for help because they stated that:

"I don't need it all the time"

With repeated cuts to social care funding, and increasing reliance on family and friends to care for individuals, employers have an important role to ensure that they introduce and promote policies that make it easier for individuals to take time off work without being excessively penalised financially.

Disjointed services

Carers experience significant anxieties in relation to navigating across a confusing and disconnected healthcare industry. In the words on one carer:

"It's a bit of a minefield. Carers have day-to-day challenges and the last thing they need is to find their way around [the] information"

Part of the problem, carers think, is that:

“There is a disjoint in service provision between education, health, and social services [which creates] problems [with] locating and accessing information”

There was also a universal sentiment that crucial agencies needed to be more proactive rather than reactive when dealing with carers.

Carers were, by and large, confused about how the health and social care system operated, and puzzled by the roles of different workers. There was also considerable bewilderment about the role of the voluntary sector. It is no wonder, therefore, that Carers find it challenging to work out who to ask for help and which agency is accountable if something goes wrong.

It was only when the individual got into difficulties that support was given. Carers also mentioned that the cared for person often has a preference not to be labelled, and this counteracts their attempts at accessing national support groups and agencies. As a result they:

“Prefer to tap into local teams rather than national”

One respondent for example, had traditionally relied on the support of family and friends living close by, rather than solicit support from organisations as they were habitually observed as being bureaucratic and time consuming.

Where support was available, one respondent thought that it lacked harmonisation because the various support groups and services did not communicate with each other successfully. Evidence of this can be unearthed by pinpointing duplication of provider services.

Single point of contact

There was also a:

“Lack of a single point of contact, having to deal with many different departments, agencies, people and care providers”

A central number to contact was highlighted as a necessity that could make it simpler for carers to find out information. This would also save carers significant time.

Emotional stress and wellbeing

The other major obstacle experienced by carers was around not being able to have time to themselves, which ultimately manifested as visible symptoms of fatigue, stress and depression.

On the opposing side, were carers who were satisfied by the ease of obtaining advice on welfare benefits. However, carers wanted service providers to concentrate more on the:

“Emotional, physical and spiritual health [of carers].”

Overall, a common sentiment shared by carers was that their role was an emotional one which had many ramifications throughout their life. For example, one individual blamed the lack of information and feedback on the collapse of their marriage. Another had remarked that they only cared for their partner because they had been together for so long and loved each other.

Although historically the relationship between carer and patient has focussed almost exclusively on a patient's needs, the emphasis is now shifting towards a more equal balance between the two parties in terms of the support required. Despite this, many inequalities still exist.

Carers acknowledge that their health inevitably suffers and are of the opinion that the GP is not sympathetic towards their circumstances. The

carer often has to wait until there is a crisis before contacting their GP. In the main, GPs respond well at the crisis stage. Carers also feel they have a struggle to get to see GPs at suitable times because of the impractical appointment systems which is deemed to be inflexible.

One respondent had not had a carer's assessment. Similarly, the GP did not:

"...ask about my health"

Although the respondent had openly admitted that their health had not suffered as a result of their caring role, they would still have valued a health assessment nonetheless.

Another respondent had been affected to such an extent by their caring role that they:

*"...had to receive counselling from
MIND"*

However, this was not without its complications. The respondent had revealed that they had to telephone a number of different agencies before they could find a free counselling service. Since they gave up work to look after a family member, money became a key consideration in what support they could get.

Mental health was a key consideration for another respondent who had to be placed on anti-depressants due to extra caring responsibilities. They were also:

*"...awaiting a referral for
counselling"*

The following list underlines the foremost impacts on health suffered by carers who were questioned as part of this study (non-prioritised):

- Sleep deprivation

- Stress
- Depression
- Tiredness

Despite these symptoms, several carers continued in the caring role because, in the words of one carer, they

*"Simply had no choice. Even when
you're ill you have to put the other
person first and just get on with it."*

There were also mixed messages around some carers being offered health checks and carer's assessments, whereas others were not. In fact, guidance presented on the NHS Choices website highlights that carers have a legal right to an assessment of their own needs and may even be able to have a separate assessment based on the following circumstances:

- When they are providing regular and substantial care to someone
- When the person they are looking after has been discharged from hospital
- When looking after someone with mental health problems who is on the Care Approach Programme
- As a parent carer of a disabled child under 18

The fact, therefore, that a lot of carers are not in receipt of support is predominantly down to weak communication and insufficient awareness of carer entitlements. In a lot of cases, carers only became aware of assessments through carer support groups.

Some of the carers surveyed were extremely concerned about what would happen to the cared for person if the carer fell ill and couldn't care for them anymore. More worrying however, was the fact that some GPs had not asked about the health of the carer. However, this was not the case in the vast majority of

situations. Quite a few carers had mentioned that:

"[The] GP was helpful and offered advice"

And that:

"The GP was keeping an eye on the family"

In addition, one carer had stated:

"The GP has been supportive with medication when I approached him"

Based on the comments provided above, it appears that carers are often affected by their roles and that the support they receive could be more consistent.

Whole family support

Another angle explored by respondents was around obtaining support as one family unit. For example, carers sought somebody who would appreciate the patient's circumstance, and who would visit the house and talk to the patient in the presence of family members – especially the carer. This is crucial, particularly as many people who are cared for have mental health issues and may not fully understand the information communicated. The carer mentioned that:

"Family and friends can't cope with restrictions placed on people in care"

Support groups & services

Another respondent would have liked to have been part of a support group for carers. In fact, there are many agencies that support carers such as Carers UK, Rethink, or the Alzheimer's Society. Part of the problem may be, however, that these organisations do not provide support in a way that is appropriate for the carer. For

example, carers may be incapable of attending events because of excessive travel distance.

Experience of using support services varied depending on who we spoke to. For example, one carer had stipulated that they were offered access to support services but that:

"...they appear to be for people who don't work instead of for people who are trying to hold down a job."

Several carers had indicated a need for additional support with their caring role, as well as the opportunity to talk to someone who was in a comparable situation. Support networks delivered via voluntary organisations, such as Approach, CASS, NSCA and MASE, were deemed as a vital life line for many carers – especially for uncovering information about medical conditions and financial entitlements.

A wide-range of support mechanisms were requested by carers, which can be succinctly summarised as follows:

- Having the ability to contact someone 24 hours a day
- Regular health assessments for carers
- Greater support from GPs and healthcare professionals
- Emotional and psychological counselling
- Support to find flexible education and employment

Support groups presented a number of direct benefits for both carers and the cared for person. For example, at one focus group session carers stated that the group had recently provided anxiety training and also introduced wellbeing days which allowed individuals to have complimentary therapies (such as tai chi and reflexology).

However, perhaps the most advantageous aspect mentioned was the support received from other carers at these gatherings. Carers in general welcomed the opportunity to discuss situations with other carers who were in a similar position. It was through these regular engagement activities that knowledge was exchanged and advice communicated.

Support groups also provided an opportunity for carers to take a break from their caring responsibilities, albeit for a short time. Carers were sometimes given the option of bringing their partners to support groups, or have the cared for person looked after separately. This allowed many carers to relax knowing that their partners were being supported and appropriately looked after.

A small but well received example of how a support group helped one of its members is demonstrated below:

“The Hospice brought a lovely Valentine’s day card for my husband to give to me which was fantastic. Just an example of how they go above and beyond the call of duty. It’s the little things like this which make such a huge difference”

The focus group concluded by saying that:

“There wasn’t the help 10-15 years ago, compared to now”

Often having a life outside of caring depends on whether the cared for person wants somebody else to come into their home. Carers who pay for additional support from outside providers feel let down – particularly when they pay for 30 minutes of support but only receive 10-15 minutes. This is often because they are rushing off to the next patient, and use the paid for time as travelling time.

One carer recounted how her mother had a weak immune system and was very susceptible to respiratory attacks. As a result, she informed the carer organisation that under no circumstances should they send someone to the house with a cold. However, despite this communication, the organisation still sent ill carers to the home who had to be turned away. The carer further commented:

“So I ended up doing everything myself because I have no faith in the system and just take respite care once in a while”

Clinical support

One respondent had commented that they would:

“...like for an alert to appear on my GPs screen during a routine health appointment”

This was so that the medical professionals were continually reminded of their patients caring responsibilities and the likely impact on their physical and emotional wellbeing. However, one could argue that the carer should also take some responsibility to systematically remind their GPs of their caring responsibility.

A further area emphasised by carers was around doctors, nurses and care professionals having specialist interests in areas such as dementia, continence, or caring for people with certain conditions. Carers believed that if each healthcare professional developed a specialism in a specific area then they would be:

“More motivated to provide support”

There was an expectation that GPs should be better trained in Dementia given that it is fast

becoming a widespread condition. In fact, the carer stated:

“Our experience is that the young enthusiastic GPs are not encouraged to do the job as thoroughly as they should due to financial constraints”

Mixed messages emerged regarding the benefits of being registered as a carer with GP practices. Many carers had benefitted by informing their GPs that they were carers. In fact, most of the carers that were positive about GP practices tended to share the same GP as their loved one.

However, it was also acknowledged that there should be more details about carers as well as their needs on GP records. For example, one carer had stated that:

“It was only after a wellbeing check that they [the GP] found out that I was a carer.”

Transitions and bereavement

The transition from accessing child to adult support services was suggested as being ‘a bumpy and weak journey’ by a handful of carers. One carer had stipulated that:

“Children’s services were better, but there is a massive gap to adult services, [and] no transition support....”

An additional area for future contemplation by service providers is the void when a patient dies and the carer is left alone. In the words of one respondent, their:

“...purpose in life had changed”

Several respondents had remarked on how they became unwell when they stopped caring for someone dear to them. They would have

welcomed extra support to help with personal issues.

A large number of carers devote a significant proportion of their lives to caring for a loved one. As a result, they have a limited life outside of the caring role. However, when the loved one passes away, the carer is often left feeling confused and alone with very little support. One carer had mentioned that the support should be:

“Ongoing and not stop suddenly”

Support groups are often the only crutch carers have apart from family and friends. Therefore, by stopping them attending the groups after death, they are making it much more difficult for them to transition to a different way of life.

It was not only the lack of emotional support that affected carers. Carers were also impacted significantly by a reduction in income when their loved one passed away. For example, one carer had stated:

“I got carers allowance for 8 weeks after he died and then it suddenly stopped.”

This individual had stated that they were not 100% ready to go to work as they were still suffering from the effects of depression brought about by bereavement, but felt they had no choice but to go back into employment.

Carers had stated in the discussions that they wanted a better bereavement service to fill the gap that exists when they stop caring for someone. In other words, the transition needs to be managed more effectively.

One carer had stated quite succinctly that:

“When you stop being a carer it’s like being made redundant from a job and

you should be entitled to claim JSA [Job Seekers Allowance] because that has been your job for so long"

A lot of inconsistency was identified in how agencies and support groups dealt with bereavement. For example, the Alzheimer's Cafes allowed carers to attend for up to 12 months after bereavement, whereas CASS in most cases offered a much shorter time frame due to funding constraints.

Some carers described their experience of end of life care. Whilst many were considered as good, a number of issues had emerged around the 'patient-carer-service' relationship. For example, carers and patients were able to see the doctor before the patient passed away. However in one incident, the doctor had not visited the patient for two years prior to the final event, which was perceived as a lack of response from service providers. Similarly, in another instance a carer had stated:

"The patient had seen more people [medical professionals] in the last 10 days than in the past 10 years"

Co-production

A key priority for carers is to maintain engagement in service development. By exploiting this opportunity, agencies can ensure that carers are in receipt of services that are better tailored towards their needs. By ignoring carers views, one respondent said that they:

"Could be doing more harm than good"

It was also emphasised that care providers should:

"...realise that carers often know far more about the needs, medical

conditions, and emotional state of the people they care for than professionals".

As a direct consequence of this failure, some carers had resented being told what they already knew. This point was associated with the need to introduce a robust mechanism for support groups and service providers to discuss and share information.

Breaks and respite

Due to the nature of caring and the significant time commitments involved, many carers would like more respite and breaks to ease their anxieties. Although carers do receive breaks, they are by no means enough. For example, one carer had:

"...one hour in the morning and two hours in the evening"

However, it was not solely the breaks that people sought. They also wanted individuals they could depend on when they took a break. This was ideally somebody that they could trust and rely on to look after the cared for person, without having to worry about whether the patient would experience distress or confusion.

Another priority acknowledged by carers was the need for additional respite care. There was a feeling that specific carers were:

"Working for 24/7 for nothing, and not getting proper time off"

Related to this were remarks around establishing more quality respite centres for adults who are under 65.

Several respondents were not offered any specific support to experience a life outside of caring. However, one individual had used:

"Some of the DLA to join Virgin Active to spend quality time together as a family and regenerate."

Another carer had intimated that they didn't require support because they were:

"...coping quite well at the moment."

Despite carers emphasising how they didn't require any support, they would still welcome assessments that would advise them of their entitlements.

One respondent had accessed a carer's respite fund which subsidised a two-night break. However, several carers were still dependent on family and friends to ensure that they had a break from caring. For example, a carer had mentioned that they had:

"Good family back up. [I was] in hospital for 5 weeks and [my] daughters cared for my husband"

They had also drawn attention to how they preferred a family member to take over the caring responsibility because if circumstances rapidly changed (for whatever reason), they would know what to do.

Similarly, because they were not presented with any information about activities or support opportunities, a carer was dependent on assistance from:

"Only daughter and friend"

Another carer had stated:

"We go together everywhere through the church and are guided by friends at the church. But we don't get any support from elsewhere"

Furthermore:

"Have a break from caring once a week volunteering in Cannock Chase whilst my daughters do the caring"

Although some of the respondents stated that they didn't get any support or breaks, one respondent had revealed that they can:

"Leave husband for a couple of hours as long as I tell him what time I am returning"

Other carers however, felt that they couldn't leave their partners alone:

"Didn't go anywhere without my husband as difficult to get help to sit with him"

Another carer stated that:

"I would like a break but I would worry if I left him with a stranger as he soon frets and I feel guilty about leaving him"

Similarly, a different carer had mentioned that

"Replacement care would do more harm than good as my partner is very unpredictable, and her behaviour can be very challenging"

This view was echoed by several carers:

"My husband gets agitated very quickly when I am not with him.....my husband would not cope with a stranger sitting with him if I went out"

The reason for the lack of respite varied but a few respondents had suggested that it was mainly down to the patients. For example, they either didn't like the day care centre or were

refused it because they didn't meet the criteria. For example, one individual had stated:

"[He] tried day service but he didn't like it and is very unhappy. Not interested in activities with other people so needs 1-2-1 activities and support"

Where respondents did receive support it was enormously appreciated. In the words of one respondent:

"The day care centre is great as it gives me time to do errands and get jobs done"

These breaks reduce the psychological burden and stress of caring for someone.

Another key issue acknowledged was around designing a system that allowed carers to take a break away from their caring responsibility. In fact, many carers had stipulated that whilst the number of days respite currently received was tremendously valued, they would like more if the opportunity arose. Many carers therefore would often be dependent on family and friends to tend for the cared for whilst they took a self-funded break.

Respite care is important for carers. However, some patients have extremely complex needs. For example, one individual disclosed that they were looking after someone who had to be PEG² fed (fed through a tube in the stomach) every three hours. The carer had undertaken the PEG feeding role for a number of years and considered herself an expert in its application. Due to the proficiency she has acquired, she finds it challenging to trust carers who may not be as experienced as herself in the technique.

As a result, she is reluctant to take a break for more than three hours at a time.

Many carers have complex needs which need to be met, however the services are not always available in a way that suits them. This puts an intense burden on carers, predominantly because taking breaks away from the caring role can be difficult. A carer had stated that:

"If the carer isn't healthy the patient doesn't stand a chance. If you're tired and your dispensing medication it can be a recipe for disaster"

The subject of dispensing medications is an important one, specifically when you have an elderly couple looking after each other. If the individuals are tired, or suffering from memory disorders (such as dementia or Alzheimers) it can lead to an under or over-dosage which can be extremely dangerous for the patient. In such cases, it is important to secure support from a wide range of people – preferably whole family support – who can take over and dispense drugs in a safe way if needed.

Quality of care

The quality of care provided was at times questioned by carers:

"I couldn't trust the agency workers so went private which was more expensive but reliable and met the need very well which didn't happen through social services"

Not valued as experts

An assortment of responses were received to this question with several carers feeling supported and others less so. For example, many carers felt belittled by professionals. One respondent thought that:

² Percutaneous Endoscopic Gastronomy

*"As a parent of a child with a disability,
I don't think service professionals see
you as a carer as well"*

Another had stated that:

*"I don't feel valued by hospital doctors
and feel ignored when I try to explain
how things are"*

In this specific case, the carer – when probed further – pointed out that healthcare assistants were frequently dismissive and became disrespectful when the carer informed them that their husband was allergic to a specific type of medication.

Overall, there were countless individuals stating that professionals did not perceive them as experts in their role. For example,

*"Our doctor is a waste of time – I have
a mental review once a year but they
don't ask me how it feels being a
carer"*

And,

*"...the medical profession talk down to
me"*

There was a widespread sentiment amongst carers that as professionals did not observe carers in their roles, it was difficult for them to appreciate the impact it was having on them. For example, a carer had stated:

*"I sometimes feel [that] the
professionals live in a little bubble and
don't understand the whole picture"*

Communication was highlighted as a hindrance to feeling supported or being recognised as experts:

*"...poor communication between
professionals"*

This statement was linked to the fact that services were not collaborating equally with carers and patients. Carers wanted to be more involved in decisions that concerned the cared for person.

One respondent believed that whilst GPs:

*"...recognised the needs of residents in
the village"*

That there were other professionals that were less understanding by:

*"...not recognising the expert
role"*

Another respondent had seldom felt supported and valued as an expert care partner, and as a result had never received any support or counselling. However, this individual was beginning to:

*"...reach out and ask for some
help"*

A different carer had declared how they never felt supported or valued by service professionals and thought:

*"Emotional support, counselling, and
advocacy would be useful"*

However, on the opposite side of the spectrum, were respondents who felt massively supported through social media (Facebook) and parent support groups by the National Autistic Society, SPAN, parent partnerships and Midland Psychology.

In fact, there were many cases where respondents were supported and acknowledged as experts in the caring role by

healthcare professionals. For example, one respondent had stated:

“GPs recognise role”

Another carer had stated that:

“I feel they do listen and respect your views”

Overall, GPs were considered as quite good in recognising the role of the carer. For example

“General Practice very helpful and supportive”

And

“The doctors are very good”

It was not only doctors that were praised. Support groups were judged to be more likely to recognise carers as experts than public health professionals.

“Going to the Alzheimer’s workshops helped me understand about being a carer”

And

“Crossroads are really helpful and supportive”

Carers indicated that it was nice to be recognised as a carer as:

“Many people just see you as the wife or the husband”

However, because some organisations view you as the partner rather than the carer it can prevent them from accessing services. Many individuals don’t realise they are becoming a carer because it happens slowly in the vast majority of cases:

“You realise your partner relies on you with his life and it changes the dynamics of the relationship”

In fact, many carers only realise that they are carers late in their journey. For example one carer had stated:

“It starts by helping them with little things like tying up shoe laces and then the tasks build-up. It’s only when it starts taking over your life that you realise you’re a carer”

One carer indicated that when you see an expert (a GP/Doctor) and follow their expert advice (e.g. the patient needs medication at certain times of the day) the nurses at the hospital/ care home staff take no notice of the advice given.

The majority of carers questioned argued that they considered themselves experts in the caring role as they understood the needs of the people that they were caring for as well as what would be best for them. However despite this, some carers felt let down by professional services primarily due to a lack of respect from GPs and nurses for the knowledge they have gained. For example, in one case, professionals failed to take account of the carers judgement when conducting a medical assessment which prolonged the situation for longer than was necessary.

However, there were positive incidents captured where GPs actively sought advice and information from the carer as well as the patient, which carers felt was an indication that they respected the carer’s role as well as their knowledge.

In one conversation, a carer had highlighted how his wife had bedsores, and consequently a nurse visited and changed her pads every day

and advised the carer to do the same. Based on this initial advice the carer continued to change the pads every day until a new nurse was allocated to the patient. During the first visit the new nurse questioned why the pad had been changed every day as it only needed to be changed when it became completely saturated. This is an example of how it was sometimes confusing for carers when professionals gave conflicting information. This promotes feelings of distrust in professionals because it was difficult to see what training these individuals had had. This distrust often extended towards medical professionals such as Doctors and Nurses.

Overall, Carers had suggested that because of the lack of respect they had from professionals they had to:

“Fight for what was rightfully yours.”

In other words, it was often the person that shouted the loudest that had the most luck with getting the services they needed. Perseverance was a key piece of advice given by experienced carers to individuals that had just entered a caring role.

Emergency care plan

Some carers had mentioned that they had no emergency care plan in place in the unlikely event that they fell ill. This would have a significant impact on the cared for person. In fact, had the carer known about their entitlement to a carer's assessment the non-existent emergency care plan may have been picked up sooner.

Personal assistants

Carers frequently had to employ personal assistants to look after the patient. However, this was not considered an easy task for many. For example:

“It's hard to find the right company”

And

“Finding a PA [Personal Assistant] has been a nightmare”

Linked to this was a feeling that personal assistants thought they knew what was better for the patient than the carer. Many carers thought this was quite patronising even though the personal assistants were regarded as:

“Lovely people”

One carer had stated that after they had interviewed three or four personal assistants and eventually found a suitable one to employ, the process of sorting out contracts of employment was in their words:

“Too hard, so I employed agency staff who sorted out all the insurance, tax and national insurance”

The recruitment of PAs therefore either needs to be simplified, or carers need to be supported throughout the recruitment process. This will allow carers to choose the most appropriate care for their partners, rather than rely on an agency who may not fully understand the circumstances.

Assessments

As mentioned earlier in this report, guidance provided on the NHS Choices website highlights that most carers have a legal right to an assessment of their own needs. Whilst many carers had had an assessment, these had often taken place many years ago. In one instance for example, a carer had the assessment 7/8 years ago was not aware that they could have periodic follow up assessments if they requested them.

The general perception of carers assessments were split into two camps. On the one side some carers decided early on that carers assessments were pointless and a waste of time – particularly given the wealth of information that had to be supplied. However, on the other side were carers who had gone through the process and benefitted because they were made aware of a service or benefit that could support them in their role (e.g. respite).

In addition to this, a significant proportion of carers also thought that carer's assessments should be made compulsory for all carers. This would allow them to identify whether they were fit and able to carry out their roles in an effective manner. Carer's assessments are important because they recognise the needs of the carer as well as the needs of those being cared for. Carers felt that the assessments should be carried out regardless of the carer's age.

Social workers

Carer's experiences of social workers were mixed with some social workers significantly better than others. For example, one carer had to go to the local library to find out information about a specific benefit change. In this case, even the social worker was unaware of how their entitlements would change based on individual circumstances.

A key issue here is the fact that individual carers have had to experience numerous changes in social workers. Some were considered knowledgeable and passionate about their role, whereas others were not up to date on the latest rules and regulations. In addition, carers also felt that they were passed on from social worker to social worker and that this meant that each social worker had to learn the case from scratch. Carers thought that it would be more beneficial to speak to the same person each week.

In a specific case, a carer outlined how a social worker had visited her husband and would often sit down and take notes whilst the carer would look after and care for him. Whilst it was accepted that the social worker had to be comfortable that the patient was being well looked after, this incident was viewed as patronising and an attempt to catch them out.

Encouragingly, carers were stating in the discussions that social workers were now specialising in specific conditions rather than covering everything. This was regarded as a 'bonus' because the social workers were now considered as experts with up to date knowledge.

However, not everyone questioned had a social worker. In one specific instance for example, a carer had tried unsuccessfully to get a social worker assigned to them. It was only when the carers health deteriorated that they received access to one. The carer stated that:

"It was sad that you have to wait till your health deteriorates before you get help from a Social Worker"

The picture with regard to Social Services was mixed. Some were very praising of a particular Social Worker, whilst others said that they had one Social Worker who was very helpful and another who wasn't. There is a reluctance to complain generally or to ask for further help if the experience was negative. Some carers had no knowledge of Social Services at all and did not know that they could get assessments either for their loved ones or themselves. In one case a stressed carer with very limited financial reserves was seeking urgent respite care for her husband without knowing that she might be entitled to financial help from Social Services. In general, Social Workers were seen as being involved only for a limited period and not as a means of regular support.

The Professionals Perspective

To explore gaps in services and the needs of carers further, Healthwatch Staffordshire undertook to investigate the issues professional organisations had.

In total, 19 surveys were completed representing the views of hospitals, voluntary and community organisations, and hospices. However, it should be noted that the results were heavily skewed towards hospices which accounted for nearly three-quarters of the sample.

Barriers experienced by organisations supporting carers

Organisations generally recognised the main issues experienced by carers and acknowledged that:

“Services are fragmented across departments and don’t always have a co-ordinated approach”

This view was echoed by many organisations who collectively highlighted how a lack of communication between services as well as assumptions made about carers at the outset of the interaction, had resulted in many carers slipping through the net.

Linked very closely to this was the issue around the dynamic relationship between carer and patient. Due to the constant changes, it was very difficult for health professionals to provide advice and even more complicated for carers to navigate the environment in order to access services. In addition it was stated that:

“Accessing carers can be difficult as they are so involved in their role, and they don’t always have time, or see the priority for them to be looked after themselves”

A shortage of suitably qualified individuals to support carers was highlighted as a potential area of concern by many organisations. For example, one organisation had stated that:

“There is generally a shortage of availability at times for staff who can support the person at home whilst the carer has a break.”

Generally, it was agreed that this was primarily down to a lack of resources which meant that there was:

“...not enough staff to help with sits”

However, it was also noted that:

“Services are a postcode lottery”

In other words, the type of service carers received was not geographically consistent or uniform across time horizons and this often confused carers.

There was also a lack of availability of structured support services for carers from the outset of a patient’s journey.

The time commitments of carers was also flagged as an issue by organisations. Some organisations had stated that it could be difficult for the carer to take time away from their responsibilities to attend appointments particularly as:

“There is no readily accessible respite sitting service”

And also there was:

“A lack of respite care available for short stay or with day services”

Another organisation had stated that:

“They [Carers] feel tired and under pressure and are therefore often reluctant to use carer support groups as they see it as another thing they have to fit in”

Furthermore, one professional offered the following comment:

“... I have had many clients on my caseload who have been carers and I’ve seen them whilst they are carers and when they are bereaved. At times I have experienced carer’s lack of time as a huge barrier to offering them support. They don’t value their own needs so don’t prioritise their own appointments. This means we are unaware of their issues and can only offer limited support”.

In addition, it was highlighted that extended families often dip in and out of caring for the patient and are therefore often missed in terms of emotional support. Even direct family can find it hard to open up about their feelings when the patients are in close proximity.

Upon discharge from hospital, one professional highlighted that it can take time to reinstate carer support packages as needs may well have changed. There was therefore an indication that support workers would need a lot of time to reassess both a carer and patient’s needs and problems.

Difficulties experienced by organisations in identifying carers and their needs

Some organisations felt that:

“Carers do not say what problems they face, or feel that asking for more help is a poor reflection on them and their abilities.”

As a result of this they were often reluctant to accept help. However, this was not the case in the vast majority of cases where carers would like more help than organisations can physically provide.

In other instances, carer’s needs were identified by organisations, but the patients were unwilling to have the additional help. Therefore, the decisions made by patients often had a direct and profound impact on carers who were often desperate for help but restricted by the cared for person’s wishes. However, even when carers wanted support, there were often unrealistic expectations of what was actually available.

Because carers do not consider themselves as carers, they often do not communicate their needs until it’s too late. They often see themselves as partners first and then carers second. As a result of this they don’t recognise the impact that the caring role has until they hit crisis point. However, organisations often experience difficulties in informing the carer that they are struggling to care for or meet the needs of the patient.

Organisations often observed relationship breakdowns brought about by carer fatigue and anxiety. And they often stated that there was a lack of structured user friendly information packs to support carers access services.

Although many organisations offered one-to-one support, they stated that carers couldn’t attend due to time constraints. Despite organisations trying to find a way around these barriers, such as offering telephone support or referrals to social services, uptake of services tends to be low. In addition, carers don’t think that their needs are important, so even though the support is available they don’t take it up because they are too busy with their caring responsibility.

One organisation had mentioned that following a death, carers can be overwhelmed with emotion as they are focussed on the practical side of caring so don't deal entirely with how they feel. It can therefore be hard to reach and support them particularly if support is not a priority for them.

The aspects of carers services work well

Organisations generally felt that carers received a good level of service once they were in the system with the opportunity to access a wide variety of options from one-to-one counselling through to more practical support.

One organisation had stated that it was the emotional support and information sharing that really worked well at support groups. This was because they often viewed support groups as a safe haven away from the pressures of the caring role. They also gave the carer an opportunity to have a break with the person they are caring for being supported outside the home environment.

In fact the emotional and psychological support offered by organisations is extremely important. This includes complimentary therapies as well as counselling services. In addition, many organisations found that day courses for carers with life limiting illnesses were extremely valued by carers, as was the fact that in most cases the support was provided with a quick response time.

The key issues raised by carers

The response received to this question was quite varied however, a number of themes emerged.

The first area of concern raised was the appearance of some care agency staff. One relative fed back to the organisation that:

"Two individuals turned up to care for her elderly father. One of them was

wearing a hoodie and jeans and the other had facial piercings and smelled strongly of cigarette smoke"

This family were desperate for help with care but felt vulnerable and unsettled by the appearance and the manner of staff who arrived. This is an area that obviously needs to be addressed, particularly if it is preventing carers from receiving support.

Linked to this was another comment around paid carers who come in from external agencies. In some instances they were viewed in a negative light because they didn't demonstrate trustworthiness or displayed a lack of motivation. For example, the organisation had mentioned:

"...being late, doing tasks without being asked, poor communication skill, treating the ill person like they aren't a person, behaving in strange and inconsiderate ways, and having a new carer every day so they have to learn the patient's needs every time."

These issues can often distress the person they are meant to be caring for and so the carer ends up having to accompany the paid carer to ensure the job is being done correctly. The ethos is therefore not on client centred care but around convenience to the paid carer.

There was also an initial lack of support during the early stages of caring. Many carers had lacked knowledge of where to go for information as well as what level of support was available to them. Linked to this was the fact that professionals often lacked skills in their ability to provide support for carers at key points of the journey and was often left until the carer hits crisis point.

Organisations also fed back how carers were concerned around what would happen if something happened to them. Even though emergency planning existed to support those carers they were still worried. There was therefore a fear that they could let the patients down if they fell ill leading to feelings of guilt and stress.

The importance of overnight care was mentioned quite a lot by organisations. In fact one statement stood out as particularly relevant:

"If a carer has a good rest overnight they are more likely to cope the next day"

However, the main issue with this was a lack of qualified night sitters particularly at the time they required. This was a particular problem for carers of people with dementia.

Finally, it was identified that there was an issues of:

"Scaremongering"

By the current government which led many carers and patients into thinking their benefits and support will be harshly evaluated and stopped unless they met stringent criteria.

Many carers are experiencing considerable problems in getting help with continence treatments for individuals they care for. The process seems to be very lengthy and difficult and at the end results in only 2 or 3 continence pads per day which is not sufficient. Carers often wait a long time at each stage of the process and are asked to try other things before continence pads are issued – e.g. some carers asked to record drinks consumed each day and volume of urine excreted which is very time consuming and difficult to do on top of other

caring roles. It can also upset and agitate the person they are caring for.

There are currently no services available for adults with Autism. Individuals that fall in this category cannot access mental health services, and parents of adults with autism are getting older and finding it harder to support their adult child. Agencies like CASS find it very difficult, as there is no support they can signpost these families/carers to.

Case Studies

Case Study 1: Jean was recently thrown into a caring role and recounts her experiences

I don't think I ever considered myself to be a carer until early last year when I had to provide personal care for an elderly relative. For nearly 9 years before that I had provided a lot of social and practical support for [Arnold] including having Power of Attorney and being the first point of contact if he needed any help but I didn't really think of that as being a carer.

I got thrown into the caring role when he was discharged from [a hospital] with a catheter. The discharge information was virtually non-existent. The arrangements had covered checking with him that he understood how to empty and change his catheter bag and generally how to look after himself in that area but no-one had taken into account that with very limited mobility and little use of one hand he wouldn't physically be able to manage it.

We were lucky that a District Nurse visited the day after discharge and immediately identified that [Arnold] couldn't manage. She also listened to my views. The nurse asked me to look after his catheter and empty his bag and help him generally 'just for a day or two' until she could get a care package in

place. I didn't really feel as if I had a choice as there is no-one else.

It was over 5 weeks later before I was able to pull out of this task as care staff were coming in to do it and eventually a key safe had been installed.

That whole period was a nightmare. It was very tricky for both of us. We knew each other well but I'd never done any personal care for him and here I was having to change his bag. Then I really had to get into practical mode as he had some bowel problems too so I was cleaning up after him.

I had to plan my time around visiting twice daily to deal with the catheter, to generally see he was alright and help him get ready for bed in the evening. Fortunately, I had just retired that very month otherwise I dread to think what would have happened to him because I just would not have been able to provide that level of support.

I had a relatively good understanding of which organisations are responsible for providing what sort of care and I didn't find it too difficult to get the information I needed but even so I struggled terribly. The individual staff were all really good but the systems let them down. There were cracks in the services when dealing with different agencies and even within the one integrated health and social care provider. At one point I was told by the District Nurse it would be quicker for me to make the referral to social care than it was for her, even though it was the same organisation. I later discovered that some of the delay was caused by the fact that the fax number the District Nurses were using for referrals was no longer the right number. I eventually got the right telephone number to refer myself from the County Council website and they hadn't been providing the social care service for 11 months by that time.

I felt as if I was constantly on the phone chasing up support. One day I counted 21 calls to the Clinic; in fact I gave up ringing at all and just went round there sometimes

pushing notes through the door out of hours. Sometimes they weren't even open during normal hours and there were no opening hours on the door. I since learned that the staff were having to cover another clinic too. I've no idea what I would have done at work; you can't be ringing people 21 times when you are supposed to be working.

After 5 weeks and within days of our planned holiday the domiciliary care package was put into place but the key safe was still not there so I still had to go twice daily to let the carers in and lock up after they left so I told them they might as well not bother if I had to go anyway. No-one seemed to understand this and I think they would have been quite happy to have just left him all night with the door unlocked. By this time the Home Care Assessor was getting frustrated and said 'I don't know what you want me to do [Jean]. Short of going round and fitting it myself I don't know what to say'. She just didn't seem to understand that I could not have gone away leaving him like that. The key safe arrived the day before we went away and five and a half weeks after [Arnold] came home.

The Care Agency were really good. Once the package was in place [Arnold] was well supported and thankfully the catheter was removed after a while. [Arnold] decided not to carry on with the carers because he wanted to get up and go to bed when it suits him. He manages now with just our help but we do not have to do the personal care now. I am aware of support for carers but I have never had to care 24/7 so I didn't need a break. I get a lot of help from my husband, for example he helps with a lot of practical jobs. I did have the opportunity to raise my concerns with the Partnership Trust. They listened to all my experiences and the manager there was very responsive. The Managers and the Trust quickly addressed the issues I raised.

I would also like to mention that when [Arnold] was in A&E and in hospital we rang lots of times to see how he was and asked that he be told that we had rung and that we

were to visit him but no-one had told him. He had been worrying because he hadn't heard anything from us.

Case Study 2: Stephanie cares for her husband who has dementia

I care for my husband with dementia who developed symptoms in 2002 but was only confirmed as a sufferer in 2004. I am normally a copier and looked after my husband without any professional support for a long time, with the back-up of my daughter. She works full-time but calls to see us most days and occasionally looks after my husband to give me a break. My husband doesn't recognise that he has a problem, but cannot contribute in any way around the house and relies on me for everything. Over the last year he has deteriorated greatly. He has become doubly incontinent and can be verbally aggressive with me and pushes me or threatens me physically.

Managing his toilet needs is a major preoccupation and I have been struggling to get anyone to understand this. The services have really let me down and I believe if I had more responsive help from the doctors and continence specialists I could have carried on caring for my husband for longer. But instead, my health has suffered – I have been under considerable stress for about 9 months, with high blood pressure and a bad back and I am now at the end of my tether. If it hadn't been for my friends at the Alzheimer's café and the MASE groups and the support of the volunteers and workers there I would have completely cracked.

My husband's aggression towards me is mainly associated with his toilet habits as I have to be on top of these all the time. I am a very clean person and have to be constantly changing pads, clothing, bathroom floor, furniture, beds etc. because my husband can leak at any time (bowel and bladder). Because of my bad back (am in constant pain) this is very difficult to manage as my husband picks up on my stress and irritability.

In June 2013 I asked for help from the continence service but there was a long delay before we saw anyone. In August the assessment started but I had already been trying to manage my husband with double incontinence with inappropriate pads that I had brought myself. I was told they could not supply pads until my husband had had a series of tests including measuring his fluid levels and faeces levels. This was impossible with my husband because of his dementia as he was not able to cooperate with this. I therefore struggled on with a wet and dirty bed (we have to share a bed as my husband doesn't cope if I am not there) and I was constantly having to try to toilet him in the night and change bedding without the most appropriate pads/sheet as no one issued me with any emergency supplies or gave me any advice.

The GP tried my husband on tablets but these made him ill. I kept ringing the continence service number but it was always on answerphone and nobody got back to me. On 6th September the nurse called again and said that we couldn't have pads as the chat didn't indicate that there was a problem.

I don't feel valued as an expert carer. I said that I would have to make a complaint and some pads were ordered but these were no good. The CASS worker then made a case on my behalf and asked for a new continence nurse for me. Eventually another nurse came on 14th October who was more understanding and said she would order larger pads (samples). However, nothing happened again on 7th Nov I reported this to my practice nurse at the surgery but I didn't receive them till 23rd Nov. These pads are by and large working with experimentation with different pants that I have brought myself (the NHS pants didn't work at all). I have also had problems with the day pads that were issued. This wasn't resolved until April. As you can see I have not had very good service and feel very let down. Thank goodness for the volunteer at the Alz Café who took the case up on my behalf.

I have picked up a lot of information gradually by attending the Alz cafes and MASE. The Alz Café used to have regular speakers who gave us good information about benefits, resources etc. I knew about respite but thought I was a coper and would never need it. I now realise I do.

My husband attends day care 5 days a week and I will very soon need him to be in permanent care. The social worker is now helping me with this. CASS helped me with a contingency plan so that emergency care can be arranged through Crossroads if necessary. I would have appreciated knowing the diagnosis right at the beginning and can't understand why I wasn't told. I feel I have really struggled to get my concerns across and lost faith in GPs and nurses, apart from the continence nurse in November who understood. However the system for getting pads doesn't work and having a clinic with no admin backup where you have to leave a message and no-one gets back to you is really unhelpful. I am a proud person who doesn't ask for favours, so when I ask for something I really need it.

The Alz cafes and MASE have been life savers for me as has Roller Mill Day Centre who are brilliant with my husband. It is further for him to travel than the local Day Centre but that didn't meet his needs so I preferred him to go to Penkridge even though it meant more toileting problems on the bus. I do get all the financial help that is available (the CPN helped with this) including the Carers Fund from CASS for which I am very grateful. In all, my experience has been horrible. Thank goodness I am only 71 years old and not a lot older.

Young Carers

This section presents a brief summary of primary research undertaken by Staffordshire County Council into young carers – in particular their needs, the issues they face, and the support carers receive.

At the outset the intention had always been to supplement the results with information accumulated by Healthwatch Staffordshire. However, despite broad attempts at engagement, the response rates were extremely low and have therefore not been incorporated as findings into this report. Nevertheless, this does indicate that engagement with young people was more difficult than initially anticipated. In fact, a recent radio talk show (Six-Towns Radio) highlighted how young carers were often fearful of talking to individuals about their caring roles because it may highlight safeguarding issues.

Analysis

The following analysis is based on the results of 17 partially completed questionnaires. Due to the low response rate, it is difficult to undertake any robust qualitative analysis of the data. Hence the analysis will only report on trends and qualitative feedback.

The majority of respondents were 16 years of age. The youngest carer was 10½ years old and the oldest was 18. Nearly everyone reported that they were a family carer – only one was a main carer.

The vast majority of young carers preferred either no waiting lists for assessments, or would only be prepared to wait up to one week for an assessment. However, roughly half this combined number were prepared to wait for as long as it took.

Although there was an overall preference to have one named key worker, young carers generally stated that they didn't mind if other people were involved as long as things improved.

A high number of young carers had mentioned how they couldn't remember when they last had an assessment review as a carer. An equal

number of young carers had the assessments when they first started being a carer. In a couple of cases, young carers stated that they hadn't had an assessment in over 5 years. However, this information may be misleading as assessments could be so 'light-touch' that the carers don't even know they are being undertaken. For example, they may be undertaken as an informal conversation rather than a structured form filling exercise. This area requires further investigation.

Where young carers did have assessments, the assessments only looked at what support might be available to help them from their families. No assessments had looked at how either extended family or friends/neighbours could offer support, which could represent a missed opportunity.

None of the young carers surveyed were concerned with being reassessed. Similarly, the vast majority of respondents could not remember the last time the person they cared for was assessed. This provides a strong signal that young carers are being excluded from important decisions affecting the cared for person.

There was a roughly equal split in the proportion of young carers indicating that there was someone in the school that knew they were carers and that they could turn to for support. However, very few people indicated that they actually offered any support other than

*"talking to us to see if things
are ok"*

Where young carers didn't have any support from schools, they often turned to parents for advice and guidance.

There were generally low levels of young carers being bullied at school because of their caring

responsibilities. However, it could be argued that even having one person bullied at school is one too many. This is an area that needs further investigation.

Caring has a significant impact on individuals and as a result, around half of young carers had to miss school because of their caring commitments. This was typically due to the fact that they often had to accompany the cared for person to doctor and hospital appointments.

There was a mixed response when carers were asked what would benefit them at school. For example one respondent had stated:

"Advice"

Another individual was quoted as saying:

"Extra time with work"

Having additional support, as well as someone to talk to and confide in, were also areas identified by carers as being potentially useful to sustaining them with their caring role. Furthermore, raising awareness of young carers in school was also cited as a way of helping carers to deal with the extra burden they experience.

Just over a half of respondents had indicated that either their doctor (or the doctor of the person they care for) knew that they were a carer. However, despite some of the doctors knowing about their caring responsibilities, the vast majority of young carers had highlighted that they were still not offered any support.

In addition to doctors, another area of concern was around the high proportion of school nurses that were unaware that some of their pupils had caring responsibilities. As a result of the lack of input from school nurses and doctors, young carers had few conversations regarding how they felt about the caring role

with people other than a small number of friends and family members.

A widespread distribution of replies were acknowledged when young carers were asked whether they could state one wish that could improve the support they received. One respondent had stated that they would have liked:

"More knowledge [such as] who to go to, [identifying] what services [are] available to me and my family, the basics such as cooking and first aid"

Another carer had mentioned that they wish they could have:

"More frequent young carers meetings, [which include] social and fun learning opportunities"

In fact, having the support of other young carers through attendance at regular meetings was highlighted by a number of respondents as being of value.

School support was also pointed out as a useful mechanism for providing comfort to young carers. One respondent in particular, stated that they would like:

"Someone at school who understands that if I'm upset at school or can't focus, then I need a break."

And another had mentioned how schools should be,

"Made more aware of caring roles"

Where young carers had received help and support there were many accounts of how it

made little or no difference. However there were also respondents who stated that:

"I feel more confident, more safe [as a result]"

And

"Makes it easier because we can take breaks"

In other words, attending young carers groups provides like-minded individuals with much needed respite from caring responsibilities. Furthermore, groups also helped individuals overcome setbacks by giving them:

"Someone to turn to"

Carers Hub Toolkit Analysis

Using the Carers Hub Toolkit we asked carers to provide additional information around how they related to the 17 interventions. The following diagram is a 'Wordle ³' of the information collected which helps to visualise the dominant words collected throughout the exercise. In other words, the more prevalent the word in the discussion, the bigger it is presented in the diagram. So for example, we can immediately identify that information, breaks and benefits advice were mentioned more frequently by respondents than rights

³ www.wordle.net

and

activities.



Information

When we asked carers what they needed, the most common theme of the answers was *information*. It was generally felt that it was difficult to know where to go to find information and that medical and social care professionals, such as Doctors, did not always have the appropriate information. Other problems raised were that people were sometimes given inconsistent information or had to find bits and pieces of information themselves from lots of different places rather than in one place. Some respondents left suggestions as to how the communication with carers could be improved such as:

'Single point of access for information.'

'Pack given to everyone in clinics with basic information and pointers on where to go.'

'Find community support groups in a register.'

Events such as coffee mornings were also seen as a valuable source of information for carers and there was support for the use of a '*carer's advice line*'. It was stressed that information and advice must also be timely and come as early as possible.

'Don't get enough advice early on in the process.'

Money and benefits advice

Another frequent theme of responses was that carers felt that they needed more advice on money and benefits. There was concern that some people are not getting the right support and are not always informed of the allowance available.

'Not enough support regarding carer's money issues.'

'Money, benefits advice and information would be good to make sure people are getting the right help.'

There was confusion over whether there were funds available for breaks for carers, home care, equipment or Personal Independence Payments.

'What help can carers get when they have to pay for care in their home in the morning?'

'[I need] more access to funding for equipment.'

Breaks

After information, money and benefits advice the most common response from carers was that they needed support to be able to take a break from caring. Some stressed the strain that constant caring responsibilities can place on a carer, particularly when that carer does not have access to respite support.

'Remember carers need sleep.'

'No respite puts pressure on carers.'

'No respite for three years has been given.'

Some carers stressed that carers should have access to both sitting services and day centres as some of the people that they care for do not want to go to day centres. One carer also commented that for a carer to have a real break they need to be sure that the person they care for is in safe hands with properly trained and high quality staff.

'When I have got a sitter in. The carer very often rings me to ask advice. How is that a break for the main carer?'

Whole family support

It was stressed by some carers that caring responsibilities can affect a whole family and so the needs of the whole family need to be taken into account. For example, more than one member of a family may need support, or a parent may be caring for elderly relative whilst simultaneously looking after small children. One carer also felt that there was a lack of support for younger patients or family members as services were geared towards those aged over 65.

'There is no consideration for the whole family e.g. young children when mom is main carer.'

'Not enough provision for younger patients or the family under 65.'

It was emphasised that it is necessary for the whole family to receive support such as access to information or training.

'[We need] family training in how to notice changes.'

Carers shaping policy and services

It was important to carers that they were given a voice to shape policy and services. Some carers felt that they were not supported or listened to by the government and that this

would only change if carers were given a genuine opportunity to play a role in directly shaping policy.

'Government does not support carers.'

'[I want] carers being listened to and views not being ignored.'

It was considered important that carer's views were directly acted on and considered, particularly when services relevant to carers were up for review.

'Taking action on the input of views from real life carers.'

'Listen to service users as to who to give the next contract to care companies when up for renewal.'

Emergency planning and support

Some carers stated that it was crucial that they had access to the lifeline of emergency planning and support should something go wrong.

'[There is a] nonexistence of emergency planning and support.'

For instance one carer commented that they would like to see a plan for how the cared for person would be looked after in the event that their carer died, became severely ill, or disabled themselves. There was also support for greater information around emergency planning and support and a 24 hour crisis line should a carer run into serious problems.

'Emergency planning and support information would be helpful.'

Emotional support and counselling

Some carers felt that they needed more emotional support, and in some cases access to counselling. This emotional support was

needed to be able to cope with the psychological strain of being a carer and it was important to be in an environment where the pressures of caring were understood.

'Need counsellor for carers to relieve stress.'

'[I need] emotional support and understanding.'

Involvement of carers

Some carers felt that they were not kept well enough informed about the care and treatment of their loved one.

'Carers are left in the dark when family members came out of hospital or deteriorate.'

This lack of communication between health and social care professionals and carers can not only leave carers poorly informed, but can also mean that the valuable resource of a carer's knowledge and experience about the person that they care for is not utilised.

'[I am] not respected as a knowledgeable person by clinical staff.'

'Make use of carer's knowledge and insights.'

'Consultants don't treat the whole person.'

Communication between services

Another issue raised by the carers that we engaged with is the lack of communication and integration between the different services involved in care and support and the pressure that this places on the carer. This difficulty is exacerbated by a lack of shared records and up

to date, thorough care plans that all services can refer to.

'Services don't talk to each other.'

'Need shared records - in the house there are three comments books but each agency will only read their notes.'

'Carers plan not updated or comprehensive.'

A related problem is that a lack of integration between services can add to difficulties surrounding the continuity of care and confusion over which services should be accessed.

'[Lack of] continuity of care extends episodes of crisis.'

'Restructuring of services causes confusion.'

Access to services

Many of the carers that we engaged with left comments which reflected their worries surrounding the services available for the person that they care for, and in turn the strain that this placed on them as carers.

'We have waited over 12 months to see an incontinence nurse. This service is much needed.'

'Carers in dire need of more day opportunities for people with learning difficulties.'

'[I need] access to a team/hub of people who can help with practical things - electricians, plumbers etc.'

There were not only concerns surrounding current access to services, but also high levels

of anxiety and confusion surrounding the ways services might change in the future.

'Day centres are being closed so where are the users going.'

'[What will be the] impact of short term beds closure.'

Radio Talk Show

As part of our large scale, ongoing engagement with carers, Jan Sensier the Chief Executive of Healthwatch Staffordshire led a radio session in which she discussed the issues affecting carers and asked carers to come forward with their questions and concerns.

One of the issues discussed was the level of support that is available for young carers. One particular difficulty raised was that young carers can be reluctant to ask for help or access services, and that this can prevent them from getting the support that they need. This can be because if they are caring for a parent, legal guardian or other family member they can be afraid that their caring responsibilities will be seen as evidence of an unfit home and they will be taken into care. This fear is heightened when a child is caring for a parent with substance abuse or alcoholism problems.

'What kind of support does a 13, 14 year old kid have when caring for an alcoholic parent? There's Childline and the rest but what if they're terrified of getting taken into care.'

Young carers may have particular difficulties in accessing financial support, and another issue discussed was what the benefit entitlements for carers should be. For instance, one caller called in to start a debate surrounding whether carers should receive minimum wage for the role that they undertake rather than the

current carers allowance which equates to roughly £2 per hour. Another respondent that called in stated that they were unsure exactly what benefits carers could claim and how they could find out about this.

The discussion was also opened up to broader considerations of care. For example, one caller asked:

'Should there be more regulation of home care providers that are controlled out of the NHS as privatised companies? Is the care that they provide up to scratch?'

This reflected concerns that privatised home care providers may not be thoroughly monitored, an anxiety which could add additional pressure on carers. Another broader health and social care issue that was discussed was the experience and time availability of domiciliary care workers. One caller made the point that many domiciliary care workers only have 15-20 minute slots to provide care for each visit and suggested that this sometimes is not enough time to provide proper care.

'Many care workers are given 15-20 minute slots to make each visit or they don't make their targets, is that putting profit before people?'

Another member of the public also expressed unease at the fact that domiciliary care workers are not required to have basic medical training. These issues surrounding domiciliary care can impact carers in the sense that carers cannot have a real rest if they do not feel that the person that they care for is receiving high quality care when they are not there.

Another broader health and social care issue discussed was the difficulties in accessing primary healthcare for the most disabled or

vulnerable. One caller expressed worries that recent cuts in primary health care may mean that the disabled and housebound have more difficulties in accessing primary care due to a reduction in home visits by GPs.

‘Do recent cuts mean that the housebound and vulnerable miss out on proper primary care?’

There was also some wider discussion concerning where the disabled and housebound could or should access services. For example, one member of the public raised issues around the use of NHS 111 to be directed to other services because NHS 111 is inaccessible for those that are deaf or hard of hearing. Jan Sensier, Healthwatch Staffordshire Chief Executive, assured listeners that Healthwatch Staffordshire was already aware of this issue and had taken action to tackle it both locally and nationally. There was also some confusion relating to the services which are available to the housebound and their carers. For example, one member of the public raised the problem that it is difficult for those who are housebound to access pharmacist services and was informed that pharmacist services are becoming increasingly flexible and can involve home visits.

Triangulation of Findings

Throughout the research, a vast number of common themes have been identified. However, the real value of any research lies in the ability to cross-correlate the findings across different methodologies and explore the commonalities between different respondent types. Therefore, Healthwatch Staffordshire sought to identify how the views of professionals and adult carers aligned, which is presented and summarised in this section. The letter ‘P’ denotes professional views and the letter ‘C’ denotes carer’s views.

P	• Services are fragmented due to a lack of communication
C	• Support lacks harmonisation because services don’t communicate with each other

P	• Lack of consistency in services
C	• A lot of inconsistency in how agencies dealt with carers and bereavement

P	• No accessible respite sitting service
C	• Carers had to fund any additional day/night sitting services out of their own pockets

P	• Carers feel tired
C	• Carers don’t have time for themselves which manifests into fatigue, stress and depression

P	• Carers don’t value their own needs
C	• Carers have no option but to continue in their caring roles despite their own health concerns

P	• Carers can be reluctant to ask for help
C	• Carers find it challenging to work out who to ask for help

P	• Carers see themselves as partners rather than carers
C	• Carers feel it their duty to care for a sick, ill or frail relative

P	•Carers need bereavement support
C	•Carers want a better bereavement service to fill the gap that exists when they stop caring for someone

P	•Support groups are great at providing emotional support and information
C	•Support groups provide a range of excellent and valued services ranging from peer support through to advice and guidance

P	•Support groups provide a break from caring
C	•Support groups provide a break from caring as carers could bring the cared for person along with them or have them looked after separately.

P	•Care agency staff can make carers feel vulnerable and threatened
C	•Carers feel vulnerable and unsettled by the appearance and manner of staff

P	•Carers find it difficult to trust paid carers from agencies
C	•Carers feel apprehension and anxiety with different care staff

P	•Lack of support during early stages of caring
C	•Carers only understand their entitlements late in the journey

P	•Lack of emergency planning support
C	•Some carers had no emergency care plan in place if they fell ill.

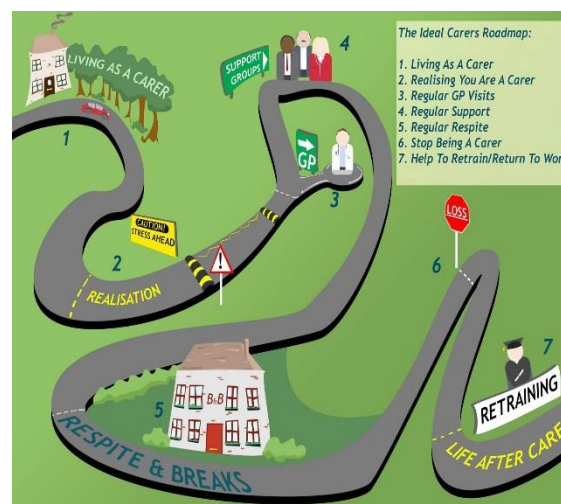
P	•Continence support is weak
C	•Need more responsive help from continence specialists

Timeline

Based on information extracted from the interviews and focus groups, we produced a number of carer journeys to highlight the points at which interventions by service providers are currently occurring as well as where they should in an idealistic scenario.

The first map therefore describes an ideal carer's journey and the second illustrates the journey as it is now. It's fairly evident that the ideal journey is much smoother and unobstructed than the journey as it stands now (larger versions of these journeys can be found in Appendix 8).

An ideal carer's journey:



A disorganised carer's journey:



Conclusions

This report has been based on information extracted through extensive engagement with a wide cohort of carers across Staffordshire. Whilst no specific claims are made about how reflective the findings are of all carers across Staffordshire, we can however state that the views of over two-hundred carers were gathered, which has brought to light a number of common themes shared by individuals, professional and organisations. These can be broadly summarised as follows:

- Carers feel excluded by clinical specialists and as a result they feel undervalued.
- A lack of communication between carer organisations leads to a lack of coordination.
- The absence of relevant information results in a healthcare industry which is difficult to navigate. Better signposting and a single point of contact is required.
- There is an extensive need for financial support – predominantly because carers have to sacrifice work and find applying for benefits difficult.
- More employers need to acknowledge the role of carers, especially given that carers need to juggle both work and caring responsibilities.

- The transition from child to adult carer services, and from caring to bereavement, is weak and requires better management.
- Support groups are valued but there ought to be greater flexibility in opening hours.
- A lack of support for incontinence is a significant area of concern, especially as it affects so many people.
- Carers acknowledge a lack of emergency planning support, as well as the need for emergency care plans.
- More robust and flexible carer's assessments would be welcome.
- Recruitment of personal assistants can be complex, particularly when there are trust issues.
- GPs need to acknowledge the issues faced by carers.
- Carers find it difficult to enjoy a life outside of caring.
- Carers have difficulties in getting GP appointments that are convenient for both them and the cared for person.

We also made a number of significant findings in relation to young carers. The first point that stands out, and is a key consideration for any future work with young carers, is how to effectively engage with a varied cohort of young people when many have a perceived fear of talking about their responsibilities with officials. We are not entirely sure why this is the case, however evidence gathered on a recent radio talk show points towards a fear that young carers might be taken into care due to safeguarding issues. This represents a significant problem because services are unlikely to improve without in-depth feedback from young carers.

A carer's assessment presents young carers with an almost perfect opportunity to inform social services about the things that could make caring easier for them. However, this research

highlighted how many young carers could not even remember the last time they had an assessment.

Young carers spend a considerable part of the day in schools and therefore schools present an ideal opportunity to identify the level of support an individual might need. However, at the moment very few individuals actually received any meaningful support and it is suspected that there is a sizeable cohort that are hidden carers.

Knowing that young people are carers helps doctors to understand their health needs and may even give them better access to GP services. Yet this research highlighted that not everyone knew of their caring responsibilities or offered any meaningful support when they did.

Support groups provide a valuable mechanism for engaging with young carers regarding their fears, worries or concerns.

The main findings also concluded that there was significant alignment between the messages given by both carers and professional organisations. For example, both parties agreed that services are fragmented, support groups are valued and that carers feel tired and fatigued. There is also agreement that carers don't value their own needs and that carers can be reluctant to ask for help.

Overall, Healthwatch Staffordshire could identify three priorities emerging for carers:

4. *Respite care provision* – as most carers need a break from their caring role
5. *Finance* – information on what financial support carers are entitled to receive and support to fill out forms. Many carers felt that if it wasn't for support groups they would not have realised their entitlements to specific benefits.

6. *Information, advice and support for carers own health* – currently carers have to find information out themselves.

In terms of next steps it is important to understand how carers should be involved in the design and delivery of services so that providers and commissioners can better meet their needs. This requires the establishment of an ongoing mechanism for young carers, adult carers and professionals so that they can benefit from co-production opportunities.

Recommendations

1. Greater collaboration is required between the NHS, Social Care, and community and voluntary organisations so that they can provide a joined up approach to information sharing
2. All carers should be assessed regularly using a flexible but robust approach
3. A checklist should be given to all carers at the beginning of their journey as part of a comprehensive information and signposting pack.
4. A central hub should be created which gives carers flexible 24 hour access to information, advice and guidance
5. Carers should be given greater recognition for the role they perform
6. Greater transitional support is required between young and adult carers and throughout bereavement.
7. Greater flexibility and availability of GP appointments for carers
8. GPs should be monitored in respect of the support and signposting they offer to carers
9. Continence services across Staffordshire need to be improved
10. Co-production mechanism should be developed
11. Create an engagement model that encourages young carers to provide

- comments in a safe environment where they feel both comfortable and confident
12. Ensure that assessments for young carers are both formalised and regularly undertaken
 13. Ensure schools are more proactive in identifying and supporting young carers with their responsibilities.
 14. Ensure young carers are supported to talk to their GPs about their roles and their needs as carers.
 15. Encourage young carers to seek support from relevant agencies.

Appendix

Appendix 1 – Case Study Template

SUPPORT FOR CARERS – CASE STUDY TEMPLATE

This template is designed to:

- *Examine the Carer Journey*
- *To understand the Carer Experience*
- *To monitor service improvements*

Suggested Steps

1. *Identify Carers willing to participate*
2. *Decide on interview method (face-to-face, telephone, self-completion)*
3. *Use prompts (rate aspects of service, relate recent experiences, comment on best and worst aspects of being a Carer, Ask for suggestions for improvement)*
4. *Analyse the information and produce as a story. Look at themes, main issues and measure improvements.*
5. *Send the write up back to the Carer for final approval and gap filling.*

Participant Information Sheet

‘Carer Stories’

You are invited to take part in a short interview to help us review the 27 outcomes in the Carers Strategy. We are interested in hearing about your personal experiences so that we can identify ways to continue to improve the service offered to you as a Carer.

Your insights about your experience will be shared with representatives from Staffordshire Carers Partnership and others across the health and social care system. While we may talk about aspects of your experience, you will not be identified in any reports, presentation or papers arising from the project.

In sharing your insights about the Care system, any information that we collect about you in connection with this interview will remain confidential, and will be disclosed only with your permission.

We also invite you to nominate an ‘alias’ so that references to the information you provide us will not identify you. If you have any questions about the interview, you can contact the following Engaging Communities Staffordshire representative: craig.staples@ecstaffs.co.uk or on 01785 224819.

Participant Consent Form

I agree to participate in an interview regarding my recent experience with health and/or social care services.

I consent to taking part in the discussion and have understood the information contained within the Participant Information Sheet, a copy of which I have been given to keep.

I understand I can withdraw my comments at any time and do not have to give any reason for withdrawing. I also understand that I may be contacted in the future as part of an evaluation of this Carer Interview method and my telephone number or email has been requested for this purpose.

I understand that my personal information will remain confidential as outlined in the Participant Information Sheet.

CARER

Print Name: _____ Date: _____

Signature: _____ Telephone: _____

Alias: _____

Interview Template

The following questions provide a framework for the types of questions you may ask a Carer when collecting their story.

1. *Describe your journey as a carer?*
 - a. *When did you realise you were a carer?*
 - b. *Did you have a choice?*
 - c. *Was it difficult to find information? Did it get easier over time?*
 - d. *At what points in your journey did you feel comfortable as a carer?*
 - e. *If someone came to you and said they were now a carer, what advice would you give them?*
2. *Enjoying a life outside of caring*
 - a. Are you aware of the support available to Carers to allow them to take a break? Do you know how to get this at short notice in an emergency?
 - b. What is your experience of using this service?
 - c. Would you use this service (again)?
 - d. Have you had the support of peers and the community?
 - e. How would you improve the service in the future?
 - f. What additional support would you like to see to give you opportunities outside your caring role?
 - g. How far do you have to depend on your family and friends to give you a break from caring?
3. *Recognised and supported as an expert care partner*

- a. *How far do services take account of your views and wishes?*
 - b. *Do you feel supported and valued in your role as an expert care partner by service professionals?*
 - c. *What would make you feel more supported and valued as a carer?*
 - d. *How would you like to be recognised as an expert Carer?*
4. Mentally and physically well; treated with dignity
 - a. Do services pay sufficient attention to your physical and mental wellbeing? How do you currently access health and well-being services?
 - b. If you need an interpreter is one provided?
 - c. Have you any experience of using the advocacy service?
 - d. Have you ever been in need of emotional support and training?
 - e. Where would you go for help if you needed support/reassurance?
 - f. Were any problems or complaints dealt with promptly/adequately?
5. Other
 - a. Are there an adequate range of services on offer for you as a Carer and for the person you care for?
 - b. Describe the usefulness of the services you were offered?
 - c. Were you referred to the services closest to where you live? Is it more important for you to receive services close to home or is it the type of support service even at a distance which is more important to you?
 - d. Were the means of transport taken into account by staff when suggesting services?
 - e. Were you told/ given access to extra support you may have needed?
 - f. Have you been offered support with housing or equipment and adaptations to make your caring role easier? What difference has this made?
6. *Not financially disadvantaged*
 - a. Are you aware that you and/or the person you care for may be entitled to receive money and benefits as part of your caring role?
 - b. Tell us about your experiences of applying for these if applicable?
 - c. What improvements would you like to make?

Comments

(Collect Carers comments here)

Appendix 2 – Focus Group Template

SUPPORT FOR CARERS FOCUS GROUP TEMPLATE

1. Before Starting

- Ensure the room is conducive to promoting discussions. A round or oval table is best
- Make sure you (the facilitator) set the tone for discussions and put the group at ease
- Ensure that every participant is given a chance to air their opinions (including the quiet ones)
- Make sure you monitor time closely and allocate enough time to each question.

- Inform people that they have a right to leave the group at any time
- Set ground rules: switch mobile phones off, everything will remain confidential, only one person to speak at a time, there is no right or wrong answers etc.
- Do not nod or agree with any statement given by a respondent as this may put others off from giving alternative views or perspectives.
- Capture all observations including non-verbal body language and morale

2. Introduction

Activity	Introduction
Guidance	<ul style="list-style-type: none"> • Spend no more than 10 minutes on this activity • Welcome the Group <ul style="list-style-type: none"> ○ Thank them for attending ○ Invite them to sit wherever they wish ○ Remember the points in red above • Introduce the purpose and context of the focus group <ul style="list-style-type: none"> ○ Explain what Healthwatch is ○ Explain how the project came about ○ Explain the format and duration of the focus group session ○ Explain how the information will be fed back • Explain how the information will be recorded <ul style="list-style-type: none"> ○ Inform them that a note taker will be recording the information ○ Inform them that no names will be recorded or comments attributed to any individuals ○ Assure them that there is no audio or video recording equipment ○ Explain how information will be analysed and used ○ Offer the opportunity for people to leave contact details IF they wish to receive a copy of the report. Reassure them that their details will not be linked in any way to the discussions • Make introductions <ul style="list-style-type: none"> ○ Introduce yourself and co-facilitator ○ Ask group to introduce themselves • Ask if anyone has any questions before you start
Observations	<i>(Capture questions and observations here)</i>

3. Ice-breaker activity

Activity	Describe the local services to support you in your Carer role using only two words. One should be positive and the other negative
Guidance	<ul style="list-style-type: none"> • Spend no more than 10 minutes on this exercise • Make sure everyone contributes • You start the activity off by giving your word (examples: helpful, informative, courteous, confusing, relevant, useless etc.) • Summarise at the end select two areas that require further discussion (one positive and one negative)
Feedback	

4. Semi structured interview script

Question	Which support services do you currently use and what are your views on those services? Are there services which you would wish to use which are not available locally or which you are not eligible to use?
Guidance	<ul style="list-style-type: none"> • Spend no more than 20 minutes on this question • Ensure everyone contributes • Prompts: <ul style="list-style-type: none"> ○ Think about services, environment, relationships etc. ○ What are the positives and negatives of the services ○ What works well (e.g. comms, range of services, continuous improvement etc.) ○ How would you improve services?
Feedback	

Question	What are your specific needs as a Carer? How far do services meet those needs?
Guidance	<ul style="list-style-type: none"> • Spend no more than 20 minutes on this question • Ensure everyone contributes • Prompts: <ul style="list-style-type: none"> ○ Think about services, environment, relationships etc. ○ How would you like to be engaged with by agencies ○ Barriers preventing good quality care ○ Areas that need improvement or review ○ Outdated working practices ○ What negative things have other carers, family or friends said about carers support services
Feedback	

Question	What should be the top three priorities for supporting Carers and why?
Guidance	<ul style="list-style-type: none"> • Spend no more than 15 minutes on this question • Ensure everyone contributes • Split the group into two and give them 3 minutes to agree 3 priorities. • Ask them to feed back with an explanation of why they chose those specific priorities (3 minutes each group) • Spend one minute concluding • Prompts: <ul style="list-style-type: none"> ○ Better information ○ Flexible support ○ Personal budgets ○ Improved access to breaks
Feedback	

Question	Using the Carers Hub Diagram, describe what each of the 17 interventions means to you?
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Guidance	<ul style="list-style-type: none"> • Spend no more than 15 minutes on this question • Ensure everyone contributes • Prompts: <ul style="list-style-type: none"> ○ Split group into two to start a discussion ○ Use post it notes ○ Get someone to feedback what the key questions/conclusions are ○ Compare how the two groups are similar/differ
Feedback	

Activity	Focus Group Close
Guidance	<ul style="list-style-type: none"> • Spend no more than 5 minutes on this question <ul style="list-style-type: none"> ○ Summarise key findings for each question ○ Seek clarification on any ambiguous areas ○ Offer a last opportunity to provide any additional comments ○ Thank them for their support and input ○ Reassure them that we will keep all info confidential and non-attributable ○ Inform them of next steps ○ Leave Healthwatch leaflet with e-mail and Freephone details in case they think of anything else of use ○ Close meeting
Feedback	

Appendix 3 – One 2 Ones

CARERS SURVEY – One-2-One INTERVIEWS

Good morning/afternoon. I am _____ from Healthwatch Staffordshire and we are undertaking a short consultation to ask Carers about their views of local services to inform a review of the support services available to carers. We are not trying to sell anything and assure you that the information you provide will remain anonymous and non-attributable to you. I will also not be asking any personal details such as your name or address. If you wish to know the results of our consultation you can leave your details so we can send you the information but we will not attach this information to the notes of our conversation. Or you can find the results on our website from mid-May.

You don't have to answer any question you don't want to, and you can end the interview at any time. The discussion should last no more than 10 minutes and if you have any questions about the survey I can provide you with a telephone number for you to call to get more information.

1. Can you confirm that you are a Carer? YES NO

2. Carers are often disadvantaged financially by their caring role

- What financial support do you currently receive and what are your experiences of receiving financial support?
- What other financial support do you think you might need?

(Prompt: Breaks, Brokerage, Housing Support, Money and benefits advice, work and training etc.?)

<p>3. Carers are often not able to enjoy a life outside of Caring</p> <ul style="list-style-type: none"> • Have you received any support to enjoy a life outside of caring and what are your experiences (if you have)? • What other support do you think you might need to enjoy a life outside of caring?
(Prompt: Education, Sport, activities, breaks, work and training, peer and community support, family support?)
<p>4. You are an expert in your caring role.</p> <ul style="list-style-type: none"> • Do you feel supported and valued in your role as an expert care partner by service professionals? • If not what would help you feel supported and valued?
(Prompt: caring training/education, emotional support and counselling, advocacy, Information, shape policy and services Support?)
<p>5. Carers often say that their physical and mental health suffers as a result of their caring responsibilities</p> <ul style="list-style-type: none"> • Have you received any support for your mental and physical wellbeing and what have been your experiences of the support? • What additional physical and mental health support would you like to have?
(Prompt: information, emotional support and counselling, breaks, brokerage, caring support and training, activities, emergency planning and support, Work, Training, A break, Family or Peer Group Support?)
<p>6. Do you have any additional comments or questions about carer services in Staffordshire?</p>
(Prompt: What have you used, what would you like to see made available, How can things be improved?)
<p>7. What should be the top three priorities for supporting Carers and Why?</p>
(Prompt: Information, Finances, Breaks, and Support etc.?)

8. Would you like to be involved as a case study?

Yes Collect email or mobile _____

No

Appendix 4 – Telephone Interviews

Carers Survey: Telephone Script

Introduction

Healthwatch Staffordshire is currently leading engagement and coproduction processes with local carers, providers and wider stakeholders to identify the key outcomes, needs and aspirations of carers in Staffordshire to inform the modernisation and re-design of our local Carers services.

We have developed this script to capture your views. We promise not to take too much of your time () and aim to ensure that all relevant feedback captured is used to improve services in Staffordshire.

I will also not be asking any personal details such as your name or address. If you wish to know the results of our consultation you can leave your details so we can send you the information but we will not attach this information to the notes of our conversation. Or you can find the results on our website from mid-May.

1. What are the major barriers or hurdles that you have experienced in your Caring role?
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(Prompt: How have they overcome these barriers, what impact did these barriers have on them and the people they care for?)
--

2. What support would you like to see as a Carer?

(Prompt: Information, Finances, Breaks, and Support etc.?)
--

3. What are your experiences of using support services as part of your role as a Carer?

(Prompt: Information, Finances, Breaks, and Support etc.?)
--

4. What should be the top three priorities for supporting Carers and Why?

(Prompt: Information, Finances, Breaks, and Support etc.?)
--

5. Would you like to be involved as a case study?

Yes Collect email or mobile _____

No

If you care for a
family member or friend...
We want to hear from you



More and more people are providing some form of unpaid care for family or friends in their own homes.

It may be just a few hours a week or it could be daily help with essentials such as washing or at meal times.

It's vital that anyone who looks after loved ones, or friends, receives the right support – and that's

where **Healthwatch Staffordshire** comes in.

Healthwatch Staffordshire wants to find out what unpaid carers think about the services and support available and to work with them to improve things in future.

We want to give carers a voice and, most importantly, we promise to listen.

Tell us your experiences and we'll pass on our findings to those responsible for carers services.

Together we can make sure support for carers in Staffordshire is as good as it can be.

To find out more, call our free hotline on 0800 051 8371 and talk to a member of our team.



Call us on **0800 051 8371**
www.healthwatchstaffordshire.co.uk
Find us on Twitter @ConvoStaffs

engaging communities
Staffordshire

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healthwatch
Staffordshire

Appendix 6 – Findings mapped to twenty-seven service specific outcomes

Ref	Staffordshire Service Specific Outcomes	National Outcome and Intervention	Findings
1	Young and adult carers will be able to access a range of meaningful information	<ul style="list-style-type: none"> Information 	<ul style="list-style-type: none"> Carers groups like CASS and ALZ are great for providing information. Some respondents did not have any information about what support was available, their financial entitlements, services, or help in understanding what might be available Many respondents had not received information at the time of diagnosis and had to find info themselves (e.g. respite care) Respondents used social media , friends, and peer support groups for information Information is available at GP surgery but respondents had difficulty locating it. There were instances where individuals were given too much information CPN nurses were considered great at passing on information Carers often don't have time to search for information Inconsistency in information provided to carers in a similar situation People who provide information are sometimes not qualified or experienced enough to provide it Hospital staff (during diagnosis) were mostly unaware of dementia
2	Carers will feel able to make informed decisions based upon the information that they have been provided with.	<ul style="list-style-type: none"> Information 	<ul style="list-style-type: none"> Carers are sometimes not regarded as experts in the caring role by professionals and are sometimes excluded from decision making. Carers often do not receive information early enough making decision difficult. Carers can often feel overwhelmed with information and have difficulty in making sense of everything
3	Carers feel empowered to have their voice heard in decisions that affect them and the cared for person	<ul style="list-style-type: none"> Information Carers shaping policy and services 	<ul style="list-style-type: none"> Carers are often feel excluded from decisions/discussions affecting the patient Hospital doctors and health care assistants can be dismissive and rude to carers Some carers do not feel valued by professionals and thus are unlikely to have their voice heard. However, other carers feel respected. Carers assessments provide an opportunity for carers to feel that they are valued – however, it appears that not every carer has one.
4	Carers will be identified early	<ul style="list-style-type: none"> Caring Support and training 	<ul style="list-style-type: none"> Carers are sometimes reluctant to identify themselves as carers which prevents them from being identified early

			<ul style="list-style-type: none"> • Carers feel they can cope without help and support and therefore continue in the role until things reach crisis point. • GP surgeries are generally quite good at identifying carers however, there is some inconsistency in the way GPs do this. • Even when identified early carers often have to wait a while before benefits/support kicks in
5	Carers will be able to share their views and experiences about the services they have received	<ul style="list-style-type: none"> • Peer and community support • Carers shaping policies and services 	<ul style="list-style-type: none"> • Peer and community support groups are the main mechanisms used by carers to share their views and experiences. • Some carers articulated their negative experiences to GPs and Social Services but this was often hit and miss with some professionals better than others • The Citizens Advice Bureau was used by some carers • Other carers simply did not know where to go to share their experiences.
6	Carers are aware of how their views can be made known	<ul style="list-style-type: none"> • Peer and community support • Carers shaping policies and services • Advocacy • Brokerage 	<ul style="list-style-type: none"> • Not all carers are aware of their entitlements to a carers assessment and therefore not everybody's views can be made known • A lack of information and awareness on how to make views known • Carers often feel more comfortable expressing their views to peer and support groups.
7	Carers are supported to be valued and respected as an individual and having their expertise recognised. Carers assessments will recognise the knowledge and expertise of the carer. Carers assessments will be outcome focussed	<ul style="list-style-type: none"> • Caring support and training • Brokerage 	<ul style="list-style-type: none"> • Some carers felt that professionals do not value them • Health care assistants can be quite rude when carers try to challenge them • Some GPs expressed more concern with carers needs than others. However, there was some concern that convenient GP appointments were sometimes difficult to obtain. • Support groups like approach generally recognise the expertise of the carer
8	Carers assessments will be regularly reviewed to ensure that outcomes are being achieved	<ul style="list-style-type: none"> • Caring support and training • Brokerage 	<ul style="list-style-type: none"> • Inconsistencies identified in the delivery of carers assessments – some have them and others don't • Regular appointments with GPs used as a mechanism by some carers to flag emotional and health related issues
9	Carers assessments will support carers to continue in	<ul style="list-style-type: none"> • Changes and transitions 	<ul style="list-style-type: none"> • Not all carers have a carers assessment • Some assessments have highlighted the requirement to have assistive technologies at home • Some concern that where carers assessments are not provided, carers often go to the GP and are prescribed

	their caring role	<ul style="list-style-type: none"> • Caring support and training 	<p>medications (e.g. anti-depressants etc) or request/receive counselling</p> <ul style="list-style-type: none"> • Carers assessments were only one area that is used to support carers in their role. The other area was family and peer/support groups which were highly valued.
10	Carers assessments will consider the extent to which carers are able to look after their own needs	<ul style="list-style-type: none"> • Changes and transitions • Whole family support • Caring support and training • Health and wellbeing • Emotional support and counselling 	<ul style="list-style-type: none"> • Where carers had carer assessments they were generally quite happy. However, the assessments were infrequent and may miss out needs that occur later on.
11	Carers feel supported to access wellbeing services, health promotion and health checks.	<ul style="list-style-type: none"> • Caring support and training • Health and wellbeing • Emotional support and wellbeing 	<ul style="list-style-type: none"> • Some carers had accessed counselling services but others had not received any support. • In a large number of cases, support was dependent on the relationship of the carer with the GP or whether the carer had had a carers assessment • Some carers are supported to access wellbeing services as part of their attendance at support groups • Time to access wellbeing services is often an issue for carers. Many carers could not leave the patient for too long and therefore chose to ignore their own needs. There was also an issue with locating free services which often took a lot of phoning around (particularly if they are not online) • Some carers would appreciate a health assessment
12	Carers self-awareness levels surrounding their own health needs increase	<ul style="list-style-type: none"> • Health and wellbeing • Emotional support and wellbeing 	<ul style="list-style-type: none"> • While carers self-awareness about their health needs increase, they do not always follow through with accessing support as they don't understand what is available • Carers are offered a flu vaccination by their GP • Carers are often more aware of their psychological needs due to caring (anxiety, depression, stress etc.) • Regular GP appointments help to capture carer needs
13	Carers feel supported to develop coping strategies which can help avert or delay crisis situations, and maximise the quality of life for both the carer and cared for person	<ul style="list-style-type: none"> • Peer and community support • Emergency planning and support • Caring support and training • Health and wellbeing • Emotional support and counselling 	<ul style="list-style-type: none"> • Inconsistencies in support received by carers. The carers that tap into peer and support groups are generally better placed than those who do not. • Some carers feel that GPs just medicate them to help them deal with depression and stress. • Carers who accessed MIND and counselling services were generally better placed than those that did not.
14	Carers will be informed about	<ul style="list-style-type: none"> • Breaks 	<ul style="list-style-type: none"> • Some carers had received a carers respite break fund but had to find the information out themselves.

	the various options available to them for accessing replacement care for the cared for person, to enable them to have a break.	<ul style="list-style-type: none"> • Emergency planning and support • Information • Brokerage 	<ul style="list-style-type: none"> • Many carers found out information about replacement care either through support groups, carers assessments or via their GP practice. • Breaks tended to be well received but some carers had to pay for day care services out of their own pockets.
15	Carers will be able to access support to plan for ways of achieving breaks	<ul style="list-style-type: none"> • Breaks • Caring support and training • Brokerage 	<ul style="list-style-type: none"> • Some carers received a carers respite fund which allowed them to take a break • Cost of day care has risen which prevents people from using it too much • Not all carers were aware of what support was available • Support for breaks was generally viewed as a blessing • Where carers did not have support to have a break they felt that their health suffered as a result • Inconsistencies identified in the type and level of support received • Some carers often relied on support from family and friends to take breaks.
16	Carers will be made aware of the range of assistive technologies available to support independent living for the cared for person and the increased flexibility, reassurance and support it will provide in the caring role	<ul style="list-style-type: none"> • Information 	<ul style="list-style-type: none"> • Carers had learnt about assistive technologies through agencies like approach.
17	Carers will feel supported to access opportunities within their local communities.	<ul style="list-style-type: none"> • Peer and community support • Education • Activities • Caring support and training • Health and wellbeing • Emotional support and counselling 	

18	Carers are supported to plan in case of an emergency	<ul style="list-style-type: none"> • Emergency planning and support • Whole family support 	<ul style="list-style-type: none"> • Emergency planning support was limited • Most carers relied on family during times of immediate need as this was often the easiest option. However, some carers refused to burden family with responsibilities. • Carers who are suffering from illness themselves often worry about what would happen if they were taken into hospital. Would the patient be looked after? • There was an issue with knowing what support was available as well as how to access it.
19	Carers assessments will consider the carers wishes to continue to take up employment, leisure, learning and other interests and commitments	<ul style="list-style-type: none"> • Work and training • Breaks • Education • Activities 	<ul style="list-style-type: none"> • Many carers would like help in finding flexible work or education but needed some support to assist them to do this • Some carers had been disengaged from the labour market for such a long time
20	Carers will feel supported to gain access to training, learning and leisure opportunities	<ul style="list-style-type: none"> • Work and training • Breaks • Whole family support • Education • Activities • Caring support and training • Brokerage 	<ul style="list-style-type: none"> • Carers are supported to access training, learning and leisure opportunities primarily through support groups e.g. dementia training provided through approach • Giving carers access to day care centres provided them with social interaction, activities, and allowed them to go out for the day
21	Young carers have access to the same information and support mechanisms as adult carers	<ul style="list-style-type: none"> • Activities • Information 	
22	Young carers will achieve the every child matters outcomes of being healthy, staying safe, enjoying and achieving.	<ul style="list-style-type: none"> • Whole family support • Education • Activities • Health and wellbeing 	
23	Making a positive contribution and achieving	<ul style="list-style-type: none"> • Work and training • Money and benefits advice 	<ul style="list-style-type: none"> • Many carers fund their core daily activities through accessing funding such as DLA, allowances etc. However, these funds were limited and in most cases did not bring about economic wellbeing

	economic wellbeing	<ul style="list-style-type: none"> • Education 	<ul style="list-style-type: none"> • The cost of accessing day services has risen putting an increasing financial burden on carers • Many carers would like additional help to access funding and to fill out/understand forms. • Carers felt they made a positive contribution when attending support groups and sharing their experiences with other carers
24	Young carers do not feel isolated	<ul style="list-style-type: none"> • Peer and community support • Breaks • Whole family support • Activities • Caring support and training • Emotional support and counselling 	<ul style="list-style-type: none"> •
25	Young carers are able to have a break from their caring role when they need one	<ul style="list-style-type: none"> • Peer and community support • Breaks • Emergency planning and support • Activities • Health and wellbeing • Brokerage • Emotional support and counselling 	
26	Young carers are able to participate in a range of activities with other young people.	<ul style="list-style-type: none"> • Peer and community support • Breaks • Education • Activities • Health and wellbeing 	
27	Young carers are safe from harm. Increased awareness in schools and GP practices to help to identify and support the needs of young carers.	<ul style="list-style-type: none"> • Health and wellbeing • Caring support and training • Information • Whole family support • Education 	

Young carers are able to attend and thrive at school		
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