



Carers Report

Understanding the quality of life for carers in
Derbyshire



Date: June 2019

Author: Hannah Morton

Job Title: Insight and Intelligence Manager

CONTENTS

	<u>Page No</u>
1. Thank you	2
2. Disclaimer	2
3. Background	2
4. Rationale for the report	3
5. What we did in brief	3
6. Key findings	6
7. What people told us	6
8. What should happen now	19
9. Response from service providers	20
10. Your feedback	31

1. Thank you

Healthwatch Derbyshire (HWD) would like to thank all participants who gave their time to talk to us about their experiences of health and social care service in Derbyshire in relation to the quality of life for carers. We also extend our thanks to the many groups and services who supported and cooperated with this engagement activity.

2. Disclaimer

The comments outlined in this report should be taken in the context that they are not representative of all patients, family, friends and carers who have experienced health and social care service in relation to dementia care but nevertheless offer a useful insight. It is important to note that the engagement was carried out within a specific time frame and therefore only provides a snapshot of patient experience collected at that point in time. They are the genuine thoughts, feelings and issues that patients, families, friends and carers have conveyed to HWD.

The data should be used in conjunction with, and to complement, other sources of data that are available.

3. Background

HWD is an independent voice for the people of Derbyshire. We are here to listen to the experiences of Derbyshire residents and give them a stronger say in influencing how local health and social care services are provided.

We listen to what people have to say about their experiences of using health and social care services and feed this information through to those responsible for providing the services. We also ensure services are held to account for how they use this feedback to influence the way services are designed and run.

HWD was set up in April 2013 as a result of the Health and Social Care Act 2012, and is part of a network of local Healthwatch organisations covering every local authority across England.

The Healthwatch network is supported in its work by Healthwatch England who build a national picture of the issues that matter most to health and social care users and will ensure that this evidence is used to influence those who plan and run services at a national level.

According to Derbyshire Carers Association (2019):

“There are over 120,000 people providing unpaid care for loved ones in Derbyshire. Established in 1988, Derbyshire Carers Association supports carers who look after a friend or family member who, due to illness, disability, mental health problems or an addiction cannot cope without their help and support.

“Many people who are supporting someone do not see themselves as a carer but as relatives or friends. Caring for others can be complex and demanding, physically taxing and mentally draining. Carers often become so focused on the person they care for that they forget to look after themselves. To keep going it is essential that carers look after their own health and well-being.”

For more information around Derbyshire Carers Association, please visit:

<https://derbyshirecarers.co.uk/>

4. Rationale for the report

To ensure a diverse range of individuals are able to share their views on local health and social care services, HWD undertake targeted pieces of work, paying specific attention to those who may otherwise struggle to be heard.

Derbyshire County Council (DCC) carry out the biennial Survey of Adult Carers in England (SACE) which seeks the opinions of adult carers, caring for an adult 18 and over, on a number of topics that are considered to be indicative of a balanced life alongside the unpaid caring role. The survey is designed to help the adult social care sector understand more about how services are affecting carer’s lives.

On a national level, the SACE has suggested very little movement in terms of improving outcomes for carers and shown a steady decline in the last five years in overall satisfaction on what was, in survey terms, already at a low level. Locally, the SACE has also reflected a gradual decline in satisfaction, which was hard to unpick given the tick box nature of the survey, leaving DCC with some gaps in their knowledge and understanding of carers’ quality of life.

As a result, between January and March 2019, HWD engaged with carers both in, and not in, receipt of services to explore their views and experiences around the themes of the SACE. The information presented will help DCC to understand the challenges faced by carers and how they can best plan and respond to them across the system.

5. What we did in brief

To collect consistent information across the county, a series of questions were developed to provide a framework for discussions with carers, which were based around the topics of the SACE and indicators of a balanced life alongside caring.

Our engagement team visited various groups and services between January and March 2019, in order to gather the views and experiences of carers.

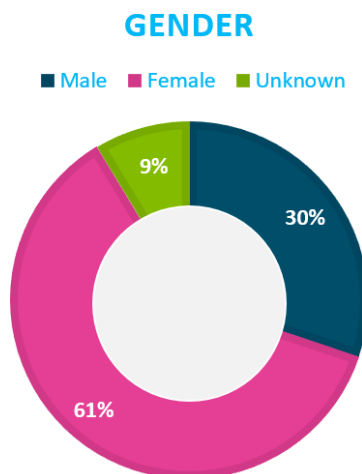
In total, we spoke to 428 carers about their experiences, and we did this in a number of different ways.

1. Through visiting groups and events which enabled us to get in touch with carers
2. Phone calls
3. Home visits.

5.1 Who we spoke to

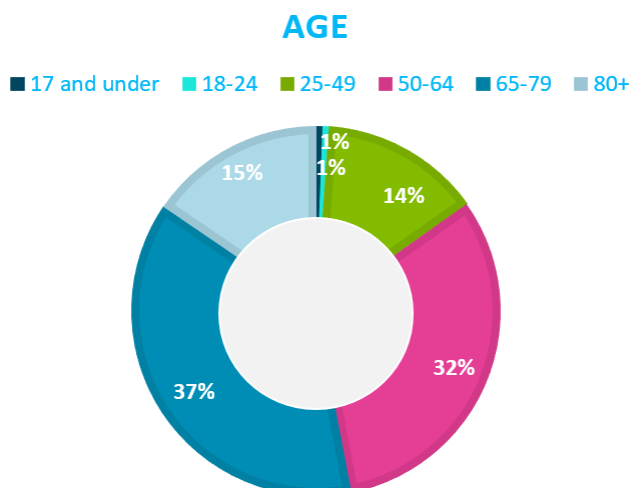
The following charts provide the demographics of those who took part in our engagement:

5.1.1 Gender:



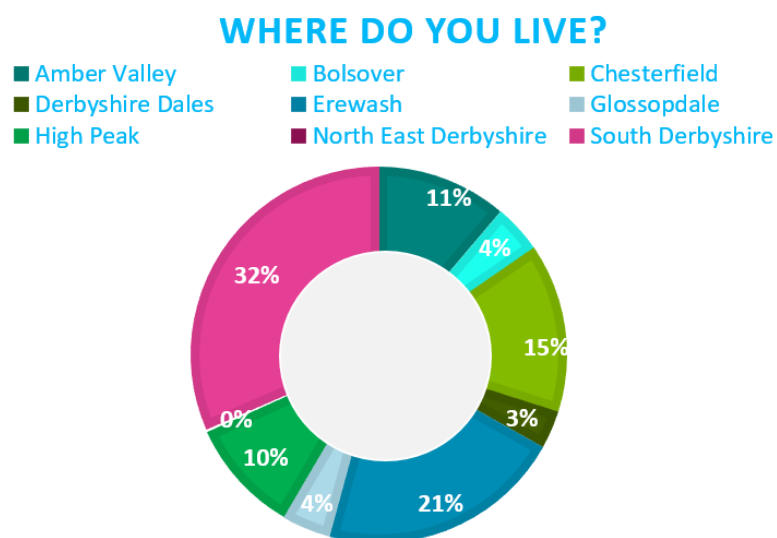
Our engagement team worked very hard to talk to both male and female carers, however only 30% of respondents were male. According to Carers UK, women are more likely to take on a caring role, there are 6.5 million unpaid carers in the UK and 3.34 million (58%) are women.

5.1.2: Age



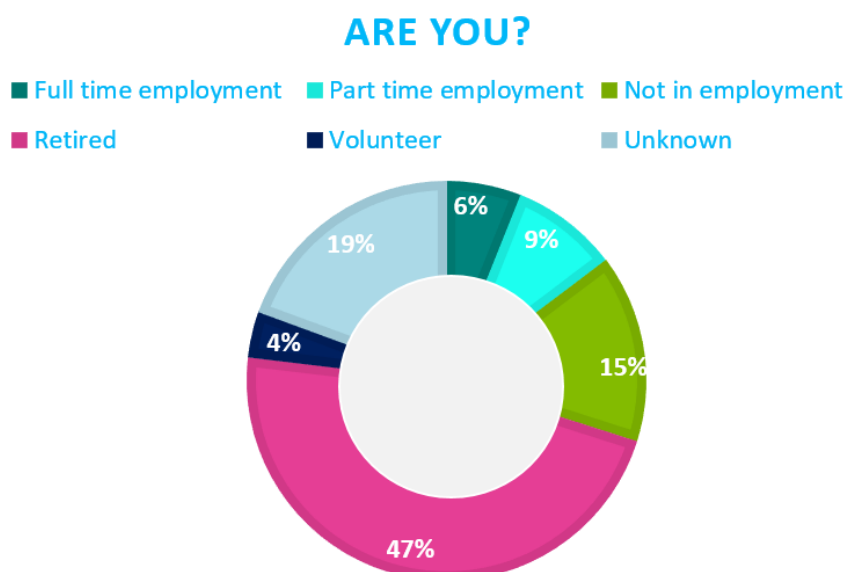
As mentioned within the rationale for this report, we were tasked to engage with adult carers. The biggest age group was 65-79 with a total of 131 carers.

5.1.3 Where do you live?



Our engagement team worked very hard to ensure they reached carers from each district across Derbyshire.

5.1.4 In addition to your caring role do you work in a paid or unpaid role?



The majority of the carers we spoke to were retired, however 6% were in full time employment and a further 9% were in part time employment.

6. Key findings

- The role of a carer impacts negatively on an individual's quality of life
- Carers have had to make sacrifices in order to care for their loved one, for example having to give up work completely or reduce their hours
- Most carers felt their health was affected, due to not having the time to book/attend appointments and for some, their caring responsibilities had impacted upon their mental health
- Being a carer is a 24/7 job and this should be acknowledged by professionals
- A huge proportion of carers explained they had very little, or no time at all for themselves and felt they had no control over their daily lives
- Social contact and the ability for carers to have a 'break' was often reduced due time, finances and unpredictability of the cared for
- Peer support was described as invaluable and many carers felt support groups should be promoted more
- Mental health carers explained they did not know where to go for support, which was often made worse because of the stigma of mental health and people not wanting to talk about it
- Many carers explained difficulties of finding the right information at the right time and felt a 'one stop shop' would be a huge benefit
- Majority of the carers we spoke to had not had a carer's assessment, many carers were not aware that they were entitled to an assessment of their needs
- A number of carers felt the assessments were focused more towards caring for people with a physical illness and not a mental illness
- Carers want professionals to take the time to listen to them and offer support when it is needed
- A high proportion of carers explained they did not feel their views or opinions were considered or valued by professionals. However, carers of people living with dementia felt very involved within their loved ones care
- A large proportion of carers were unaware of their rights, and were unsure how to find out about them.

7. What people told us

7.1 Quality of life for carers:

Most carers explained that their quality of life had reduced or changed as a result of their caring role.

7.1.1 Work commitments

A large proportion of carers were retired (47%), however some explained that they *had* to give up work completely or reduce their hours to be able to care for their loved one.

A number of carers explained, they were unable to juggle both work and their caring role, especially when the health of the person they cared for began to deteriorate, causing their caring role to increase and it was simply no longer possible for them to carry on working.

Sample of comments:

- “I didn’t have the time to do both, so I had to give up work, I would like to still be in work”
- “I still work and have altered my job so I can work from home on a computer when I have a free hour or so”
- “I had to give up work to become a carer.”

7.1.2 Impact on health

Most carers explained that their caring role had a negative impact on their health. This varied from physically not feeling very well, but just not having the time to book a doctor’s appointment so symptoms persisted and also, the impact on carers mental health due to their caring responsibilities.

A number of carers explained they had experienced anxiety and depression as a result of their caring role and had received prescription medication to help manage their mental health.

One carer explained that following a hospital admission she still had to arrange everything at home, “Even when I was ill I still had to be a carer 24/7, I had to put myself second.”

When she was discharged home she received no further help or support as her husband was at home, despite explaining to staff that her husband had mental health issues and would be unable to care for her. As a result a family member had to take unpaid leave from work to be able to care for her. The carer felt that if her husband had a physical illness there would have been support put in place to help back at home.

Sample of comments:

- “I don’t always have the time or opportunity to look after my health or go to my doctors, it would be good if you could have joint appointments to speak about your health when you take your partner for their appointments, just to see if you are OK”
- “Many carers are isolated as a result of being a carer and feel alone which affect your mental health. Being a carer is 24 hours a day, it is exhausting and debilitating and affects your health, you cannot find the time to look after

yourself. An acknowledgement of what carers do on a daily basis and how that impacts of you should be a priority for the local authority”

- “I am tired all of the time, physically and mentally”
- “If their health drops, so does yours, especially your mental health”
- A number of mental health carers explained there could be “emotional blackmail” from their loved ones at times as, “... they do not realise how upsetting they are being”
- “There is no recognition of how caring impacts our health, you are constantly worrying about the person you are caring for, who cares for us?”

7.2 Caring responsibilities

Some carers had been caring for a loved one for several months, whereas others had been caring for 20+ years.

In terms of the length of time spent caring each day varied considerably, but it was a common consensus that being a carer was a 24/7 job, even when a carer is not physically performing a caring act, they are still worrying or thinking of their loved one. It was also felt that this is something that should be acknowledged by professionals.

The responsibilities varied, some carers explained their role is often prompting and promoting self-care, whereas other carers undertake personal care for example bathing and toileting. Majority of the carers explained they have to do *all* of the cooking, cleaning and household tasks.

Sample of comments:

- “You are always on alert unless you fall asleep from exhaustion and then you do not sleep properly”
- “It is 24/7, even when I awake in the night, I worry about what the noise is that awoke me, has he fallen? Is he OK? When the phone rings you worry that is it because he has fallen, even when they are at day care or respite there are constant calls and worry”
- “He would never have a wash or shave if I didn’t tell him and remind him, he would have no idea if he smells or not”
- “Mental health carers do not have to do personal care but have to manage the household and bear the responsibility for everything”
- “I make and cancel appointments for the person I care for, I help them to attend appointments and to get out and about. I cook, clean, organise everything and pay the bills, I basically make sure everything runs smoothly”
- “I know I have it easy compared to someone who lives with a dependant relative, but this person is just a former colleague. I feel obliged to continue supporting her because she had no-one else.”

7.3 Carers time to self

A huge proportion of carers explained they had very little, or no time at all for themselves and some explained they felt guilty when they did. The majority of carers said they had no control over their daily lives, as everything revolved around the person they care for.

A very small number of carers had support from family and friends, which enabled them to get a couple of hours per week to themselves.

One carer explained, “Even though I have family I feel isolated, especially in the evenings. As a carer your role is to help the individual in the home ... we are constantly on call and going out is a big thing and sometimes day to day routines can become mundane. Having family members to help out makes such a difference, it is essential to have a strong supportive network. That said, there can be an assumption made that carers are OK and coping if they have family support. It is really difficult for me to get the support I need as professionals are not linked up, I feel passed through the system. Sometimes there is too much information and it is just too overwhelming to take in, or sometimes there is not enough information and I don’t know where to go for what I need.”

Sample of comments:

- “I just used to go out once a month to the hair dressers”
- “In the little time I have for myself, I do very little as I am tired all the time. I lie on the sofa and watch TV if I can stay awake”
- “As a carer you can feel very alone ... attending the carers support group is a lifeline where I am not alone in my struggles, I can be in a place where people can understand what I am going through and everyone shares tips to help me out”
- “My partner goes to day care once a week, but I cannot use that time for myself as I find myself using it cleaning up and sorting things out for his return”
- “My life is gone, I look out the window at my neighbours living their lives, coming and going and think why can't I do that?”
- “I feel as though I have no control over what time I do have spare, and how I use it. This is because partly society doesn’t value my care, contribution or respect it.”

7.4 Social contact

7.4.1 Impact on social contact

Many carers explained the difficulties of maintaining social contact with friends and family due to their caring role.

Some carers explained that since they took on the role of caring for their loved one, they are often unable to maintain social contact mainly due to time, finances and unpredictability of the cared for.

Some carers explained, that in order for them to go out with friends (regardless of how long for), they would need someone to look after their loved one, which costs money and not all carers can afford this.

Sample of comments:

- “My life was turned upside down, we used to get asked to do things all of the time, but not anymore as we had to keep cancelling at the last minute as my husband was not well enough to go”
- “It is very difficult to sometimes accept invitations to events. Just as I am ready to leave the house with my husband, he can change his mind and refuse to go with me. Just in the last few months, I have either missed nights out, or had to go on my own... If I do go on my own, I then spend the evening worrying”
- “Caring impacts on my ability to have a social life due to the unpredictable nature of the person I care for, and so it is hard to make plans to meet new people”
- “I just don’t have the time, I don’t see how I can find the time, caring is isolating it is all-consuming, its constant, you rely on people visiting you, it is like you are a prisoner”
- “My friends have vanished, meeting up with friends is difficult as you are restricted by your caring role, friends are not always able to meet when you are available”
- “The difficulty for me is because I run out of time as I am caring and I have no energy left so I do not want to go out as I am tired.”

7.5 Carers support groups

Peer support was described by many carers as ‘invaluable’. Many carers explained that through attending support groups, they were able to have open and honest conversations about their feelings, share experiences and advice.

One carer said, “I have been coming to [named] carers groups for a few years and it is very valuable, talking is a really good thing as you get to learn from other carers and share experiences. I need these times to spout off and I really value the time, I feel free here to share my feelings as other people who are not carers do not understand. The benefits of carers groups should be promoted more.”

Many carers felt support groups should be promoted more, as many carers are unaware of local groups. One person explained, “If the GP can remind you about an appointment they could also let you know about support groups or mention them to carers during their appointments to check they know what is available in their area.”

Although many carers are aware of the benefits of attending support groups, many are unable to do so due to time, finances and unpredictability of their loved ones. It was suggested by some carers to have more availability and flexibility of respite care as most carers just want ‘a few hours’ to themselves.

Furthermore, according to one carers groups, Derbyshire Carers are hoping to introduce a befriending service and all carers felt this was a very good idea and was something that, “Should have happened years ago and should be available for all carers if they need it.”

Sample of comments:

- “It makes you feel not so alone, others will have experienced the same thing and know what I am going through”
- “I attend a carers group specific to mental health, and this peer support is invaluable. It is only once a month, but the people who attend are very understanding as they have similar experiences”
- “Just an hour or so (of respite) once every couple of weeks would have made our lives so much better”
- “There is day care but it is from 10-3 which is of no use to us, I just want a couple of hours once a fortnight, it would do us both good to be in different company”
- “It is a catch 22 situation, you need to make sure there is some care for the looked after people so carers can attend a group and not have to worry”
- “It is a place where you can talk about anything or nothing, which is exactly what we need”
- “The group is the only social activity which I share with people. Otherwise, I don’t socialise with anyone apart from whoever comes to the house wanting something from me”
- “Services that run side by side may help, perhaps we could have activities that run alongside one another.”

7.6 Information and support

7.6.1 Finding information and support

Carers explained they found out about the information and support available to them predominantly by word of mouth, whilst other carers explained that if they needed any particular information they would ask their GP.

As previously mentioned, carers groups were again highly commented on especially in terms of guest speakers from different organisations.

Many carers explained they would like to have a ‘one stop shop’ where carers could ask a question, or share a concern in which a worker would find answers and/or information on their behalf. Most carers explained that they simply do not have time to be making numerous phone calls, research and chasing people up.

A number of carers felt that GP surgeries could do more to provide information and support to carers for example, “GP’s know which patients are carers, they should check with them and let them know about things or signpost them to organisations that would be able to help.”

In addition, mental health carers felt they received ‘very little or nothing’ from their GP with regards to information and support.

Most carers were not aware of the Carers in Derbyshire website and Facebook page, with many explaining they prefer to receive information in person or they do not have access to the internet.

Sample of comments:

- “The pressure of caring and supposedly knowing everything is often too much to bear”
- “Information sharing amongst the support group, or people you meet by chance is good to some degree, but then it is bad if you are not able to get out and about. It may also mean that finding the right information comes down to luck which is not how it should be”
- “They (professionals) often do not even tell you things when you ask a direct question, let alone offer you other things that may be helpful”
- “We haven’t got time to keep ringing people up who are never in or work, or they are part time. We want to make one phone call, and then for someone to take all of our details of what we want, and then someone would get back to us with the information they have found”
- “Mental health carers often feel lost and do not know where to go and this is made worse because of the stigma of mental health and people not wanting to talk about it”
- “I don’t see a lot on it (website), what is on it for people caring for adults, what is available for parent carers?”
- “I have seen the Carers in Derbyshire Facebook page. I have looked at their posts over the past month and realistically there is nothing posted which would really help or interest me.”

7.7 Difficulties obtaining information and support

Many carers explained their struggles of finding the right information at the right time.

From the carers we spoke to, the most difficult types of information and support to obtain were:

1. Benefits and entitlements
2. Deterioration of a loved one
3. Breaks and respite (particularly more difficult for self-funders)
4. Social activities
5. Aids and adaptations.

In addition, carers also felt additional barriers were put in place which could prevent carers being able to access the information and support they required for example:

1. Having to complete or search things online
2. Spending long periods of time waiting on the phone
3. Needing to make numerous phone calls, to various people/organisations

4. Completing lengthy documents.

Sample of comments:

- “The main gap in information is about the benefits you can get for being a carer and how to apply for it. There are also things you can get from your council which you are not told about and are not widely advertised or promoted”
- “If carers are self-funding they have to do it all themselves (research care) but they do not know what to look for and so this can cause additional stress”
- “Reliable and caring carers (who are paid) is a massive gap, I am happy to pay but no one wants to give me a break so I continue even though I am near to breaking point myself”
- “Some carers do not always feel supported as their loved ones deteriorate, it was expressed that more information is needed to prepare the carer, so they know what to expect”
- “It (breaks and respite) is all kept very hidden and almost secret so you do not find out about it”
- “I found it hard to find out about activities and support for my father to do to keep him entertained and getting some enjoyment from life”
- “The hardest things to find has been information that is reliable and up to date about arranging home care, you do not know where to look or who to ask, no one recommends anywhere and it is so hard to find someone or a company that is reliable and safe”
- “You get no help with all the forms, I have never had to do anything like this before so dealing with this and the shock and upset of my husband’s diagnosis was almost too much, do people not realise or have no sympathy?”

7.8 Carers assessments

Majority of the carers we spoke to had not had a carer’s assessment, those who had explained of the small financial benefit of doing so. However, many carers were not aware that they were entitled to an assessment of their needs.

Carers who had undergone an assessment explained they did not like having the assessment over the phone and would much prefer it to take place in person.

A number of mental health carers felt the assessments are “biased” towards caring for people with a physical illness and not a mental illness.

In addition, a number of carers explained the importance for the worker/professional undertaking the assessment to have some knowledge and understanding around the condition for example, mental health and to understand how needs made fluctuate and therefore this should be taken into consideration during the assessment.

Sample of comments:

- “The assessment made a difference in that I got some money, but I got nothing else, no information, no signposting and no support”
- Derbyshire Carers do not attend the groups or encourage us to apply for an assessment, they used to be very good and they used to meet up with you personally”
- “I would like to have the option to do carers assessments face to face rather than over the phone”
- “You and the person you care for could be in a good place at the time of the assessment, which means that you could be allocated a lower amount. But as with the nature of mental health, the situation of the person you care for and your personal needs could change dramatically from day to day”
- “I haven’t arranged a new one yet, it is a couple of years since I had one with Think Carer which was totally clued up on mental health. I keep forgetting to making an appointments as I am so busy”
- “I have had a carers assessment but it did not lead to me being referred anywhere to services for any help for either of us, so in many ways it was a waste of time. They did say I can ring them if I ever need any help or if things change. It built up my hopes but then there were no services to meet my needs or any money to pay for them”
- “Nothing seemed to apply on the form they went through, I would like the assessment to take more into account that you are caring for someone with mental health.”

7.9 Encouragement and support from professionals

7.9.1 Community mental health teams

Experiences varied, some carers had positive experiences to share and felt they were listened to by mental health professionals, whereas others felt they had to become “experts”.

Carers want professionals to take the time to listen to them and offer support when it is needed.

One carer explained, they received very little support from mental health services when their son first became ill, the family were willing to pay privately for a psychiatrist so they didn’t have to wait so long. However, they were told that if they did pay privately, their son would not be able to access other NHS help or social care support. As a result, their son waited for months to be seen and they felt that if they were seen sooner he may not have had long term mental health issues. The carer said, “He used to run his own business and employ people, now he will never work again as he has never stabilised or got the correct medication that works for him”. The family had no knowledge of mental health and felt they were expected to become “experts” and have never received any support from services.

Sample of comments:

- Psychiatrists are generally calm and listen well and tend to be more responsive and effective at making good decisions and taking adequate measures regarding medication, but again sometimes they can be negative and misunderstand the patient”
- “He (the psychiatrist) is OK but you only spend a few minutes with him and I do not have time to talk about how being a carer is making me worse and I am worried I will get very ill again and have to go to the Radbourne unit for months like I did a few years ago. I wish they could provide more help for me to take my mind off how low I feel”
- The groups felt that, “Professionals need to understand that mental health caring is not a 9-5 job, it is 24/7 and professionals need to be aware of this ... support from professionals at groups would be beneficial, workers on the ground (support workers) seem to understand the support carers need but this gets held up further up the ladder”
- “Professionals rely on the carers to be resilient and persistent and to know everything, we are not experts. Mental health carers are concerned for people who do not have a carer.”

7.9.2 GPs

There was an agreement amongst a number of carers that GPs do not have the time to really listen to their patients. One carer explained that when her husband deteriorated and became incontinent it took her around four months to be offered help, she said, “I had to go to the GP in tears before anyone would listen to how much I was struggling.”.

Some carers explained how they felt it had become more difficult for them to book an appointment for themselves or their loved one, and how the wait had got much longer in the past few years. In addition, a number of carers felt that GP appointments were not very flexible for carers, and their caring responsibilities were not taken into consideration when booking appointments. One carer explained she only got an appointment to fit around their caring responsibilities when they asked to talk to the practice manager.

In addition, a number of carers felt that GPs could do much more in terms of signposting people to support. It was explained that in the beginning carers can generally cope but as time goes by and their loved one deteriorates, this is when carers may begin to struggle and feel help is harder to find.

Sample of comments:

- “No one asks how I am feeling”
- “We knew what was wrong but it took several visits before we were listened to”
- “They [GP appointments] are not flexible at all”
- “They never think about other help you may need, they just think about whether to write a prescription or not.”

7.9.3 District nurses

There was generally quite negative feedback around the delays and that some nurses did not turn up for appointments. There were also some concerns from carers around the lack of thoroughness and continuity.

Sample of comments:

- "... or sometimes not even turning up at all"
- "They only do the bare minimum"
- "Nurses will only do what is on their sheet, they will not do anything that may have arisen after the visit was booked"
- "People with long term complex chronic conditions like to see the same person but this does not happen very much anymore."

7.9.4 Social Care

Several carers explained they have received a lack of help and support from social care services, and carers did not always feel listened to.

A group of parent carers felt there was not enough support for people with a learning disability and it was felt that once their child reached 25, support was reduced.

One carer explained, "The social worker was very critical of me and I didn't know why, I raised a concern and I now have no contact with them. I feel I have been let down by them, I am willing to pay for support but I just want help choosing and arranging it as I have never had to do anything like this before and it is hard when you are having to learn new things when you are over 75 years old. I do not think social services realise how hard it is, I have enough on with keeping myself and my husband going, let alone learning new things and arranging care. I am also living with cancer and I think social services could be more understanding of this. Yes we have money, but we still need help too."

Sample of comments:

- "They just refer you to places and you have to arrange everything yourself, most carers do not have the time, energy or expertise to arrange care whether for respite or permanent"
- "They seem to think that when you reach 25 your child no longer needs any help, our child will always need help, it is not something they will grow out of"
- "You seem to get new workers all of the time and then have to repeat everything. Why do workers not read out my child's care file as he has been linked with the council for over 30 years, why should I have to repeat everything?"

7.10 Involvement and consultation

7.10.1 Carers feeling involved

A high proportion of carers felt they had very little interaction and involvement with health and care professionals and explained how they felt their views and opinions were not considered or valued. This was particularly the case for carers of people with a long term condition or mental health.

Three carers spoke about when their loved ones medication was changed and how this affected them, they all explained they had tried to raise concerns but they were not listened to. As a result two of these people ended up hospitalised whilst their medication was changed.

It was believed that carers are not always encouraged by professionals to be involved due to confidentiality and data protection.

However, on the other hand, carers of people living with dementia felt very involved within their loved ones care.

Sample of comments:

- “Carers should have a chance to meet with mental health professionals on their own about their loved ones, as they know how things have been really happening”
- “Why didn’t they listen to us? I raised this lots of times and they just ignored me ... I felt helpless, because of this my husband ended up going back into hospital. What a waste of resources”
- “Professionals need to really listen to carers as they spend most of their time with the cared for person so they will have a lot to contribute about how the person has been, or if the treatment or medication is working”
- “It feels like luck if you get someone who wants your input”
- “My husband cannot express himself, so I have to speak for him at appointments. I have been told by professionals that they do not want to hear it from me. I feel as if I am wasting my time as they do not listen to me”
- “My wife had dementia, I felt I was always involved right from the beginning, I felt an equal partner and maybe more than because my wife did not really understand what was happening to her”
- “I have always been allowed into appointments and have been involved in discussions as my mother does not remember or understand what is happening.”

7.11 Carers breaks

7.11.1 Time for carers

There were mixed definitions of what a ‘break’ is. Some carers explained a break was going away for a few days, and for others it was just a few minutes to themselves. It was felt the key to a break would be to ‘forget about caring’. However, many carers explained this would be almost impossible.

Sample of comments:

- “I would just like to be able to have a chat on the phone without interruption, that would be a break”
- “I would like a regular break to get myself together and maybe have a coffee with a friend”
- “I would like to be able to have a walk in the fresh air”
- “Just a day to myself would be wonderful, but I know that will never happen”
- “There is not a lot I would want to do away from my wife, I just wish we could do more things together like we used to.”

7.11.2 Difficulties in having a break

There were a number of reasons as to why carers did not always have a break, or they did not have as many breaks as they would like. It was explained, that as a carer it is very difficult to ‘admit you need a break’ as some feel it could mean they are not coping. Two carers explained they had to reach crisis point before they asked for a break. However, some carers explained that being a carer really does impact on their own health and wellbeing, and it is important for carers to have some space for self-care.

Affordability and the cost of respite care also appeared to be a barrier for many carers having a break. In addition, a number of carers explained the stress of finding the right place or suitable care for their loved one. One carer explained, they were unsure whether their loved one would require support in a care home, or nursing home. They felt it had been assumed that carers know the difference.

Sample of comments:

- “Having a break is very important, especially when you are caring for someone with dementia because you cannot always have a conversation or laugh like you used to do as they are no longer the person you met or married”
- “I work longer hours than most people who work, and so I need a holiday too but it can never happen as I get a pittance for looking after my husband and saving the government so much money”
- “You have to fight to get respite care and even then the decision is based only on what the person on the phone translates it as, or from the paperwork, so most people are just turned down.”

7.12 Carers rights

A large proportion of carers were unaware of their rights, with many asking, “What are our rights?” Many carers explained they would not know how to find out about their rights, or have the time to be searching.

Some carers explained they are unable to fill in the required forms which acts as a barrier and therefore more support should be provided to carers to ensure they are able to complete the required documentation. In addition, a number of claims have to be

completed online in which also acts as a barrier especially for older carers who have never used a computer or accessed the internet.

One carer explained she had contacted South Derbyshire District Council with regards to council tax reductions, and the worker said, “If people do not ask about a reduction, then we do not tell people.” Carers felt that staff should be trained to provide consistent and correct information about reductions for carers and eligibility.

Carers felt they got ‘a raw deal’ from authorities, and many felt that in order to get what they need and are entitled to, they had to be assertive.

Sample of comments:

- “Carers would like clearer, simpler information about their rights and not having to constantly chase and fight for them”
- “They (the forms) are long and complicated and I can hardly see them”
- “It is hard to keep your head straight to get things sorted, so a lot of the time you do not bother and try to manage without”
- “I am not that type of person, so I struggled for six years and it was only when my husband got a chest infection that someone eventually did a home visit that they realised what I had been doing and coping with, that I started to get help. If that had not happened, I do not know where I would be now”
- “It [council tax reduction] is not advertised enough, it is an entitlement and we should not have to ask and beg for it”
- “We have to prove everything from our side, we should not have to do this as we are spending time caring for people and saving the government money”
- “Most of the stress comes from fighting for, and chasing what you are entitled to, we do not need this on top of losing our husbands right in front of us day by day.”

8.0 What should happen now?

1. Consider the option for carers to have face to face assessments and to ensure carers are signposted to support/relevant services following their assessment
2. Ensure that the worker/professional undertaking the carers assessments has good knowledge and understanding around caring for someone with mental health, learning disabilities, end of life etc
3. To ensure carers receive the correct level of support to effectively care for their loved one and also look after their own health and well-being
4. To have more information about what carers are entitled to (i.e. carers rights), this should be in an easy to understand format
5. Raise awareness of the ‘Carers in Derbyshire’ website and ensure there is plenty of information about local services and support for carers
6. Work to create a ‘one stop shop’ for advice and signposting
7. Ensure information around carers breaks and respite is readily available
8. Promote local support groups and the benefits of peer support

9. Look to develop services/groups for carers and the cared for, that run side by side one another
10. Ensure that carers are always involved (where possible) in the care and treatment of the cared for.

9.0 Response from service provider/commissioner

Derbyshire Carers Association (DCA): DCA welcome this report from Healthwatch, it confirms many of the issues we raise awareness of on an ongoing basis. We have written this response based on figures from our service which we hope will address the highlighted issues and show our commitment to continually improve the service that we provide.

	What should happen now?	Response:
1.	Consider the option for carers to have face to face assessments and to ensure carers are signposted to support/relevant services following their assessment	<p>At DCA we recognise that some carers would prefer to have a carer's assessment completed face-to-face as opposed to via telephone.</p> <p>The DCA aims to complete assessments in the most appropriate way for individual carers so that they can feel comfortable and valued. For this reason we offer options for home visits, office visits, outside visits at mutually agreed venues and telephone assessments.</p> <p>There is extremely high demand placed on the service. Last year we completed 2185 assessments. The vast number of assessments are done face to face and we offer choice in this matter. Whilst ensuring the assessment is both meaningful and effective.</p>
2.	Ensure that the worker/professional undertaking the carer's assessments has good knowledge and understanding around caring for someone with mental health, learning disabilities, end of life etc.	<p>At DCA we ensure that all of our assessment workers are extremely knowledgeable. Firstly, we actively advertise for staff who have prior experience in social care. All new assessment staff receive a thorough induction and a graduated period of shadowing of experienced staff. They are also supervised by experienced Team Leaders who will identify any gaps in working knowledge and ensure these are addressed by peer-mentoring and attendance at external courses run by Derbyshire County Council.</p>

		<p>Our triage team thoroughly understand the competencies of team members and can allocate assessments to the most appropriate worker for each unique situation. Senior management also regularly quality check assessments to ensure the content is comprehensive and accurate.</p> <p>The Think Carer team have transferred to DCA with their wealth of knowledge. We also have other members of staff who are mental health trained via health and social care with ongoing mandatory training continually available. Experience of staff is broad, coming from careers in nursing / care; hospice care; supporting people with life limited conditions and end of life; A range of social work backgrounds; occupational therapy and physiotherapy and SW management working with a broad spectrum of health conditions and disabilities. We have staff specifically trained in various disciplines to support the needs of carers. Possibly more importantly, there is a high ratio of staff who are themselves informal carers, with empathy and understanding of carers needs. Staff retention at DCA is high, with the same staff working with carers for many years.</p>
<p>3.</p>	<p>To ensure carers receive the correct level of support to effectively care for their loved one and also look after their own health and well-being</p>	<p>Alongside carer’s assessments, DCA aim to provide a range of training opportunities for carers, including first-aid and manual handling courses. Last year we offered 15 training opportunities and 176 carers learned valuable skills in manual handling and first aid. We also regularly offer respite activities throughout Derbyshire, striving to reach as many communities as possible. We offered 28 activities variable numbers from 6 at pamper session to 35 carers on a trip, attended these in the previous year. All of these opportunities are advertised through our three-monthly newsletter, groups, carer support teams and website. Additionally, DCA commenced a service in May introduced a telephone befriending service. This allows isolated carers the chance to talk to a volunteer once a week, providing a much needed opportunity for social contact. At present there are 4 volunteers speaking to 9 carers, with further 5 volunteers being trained with 6 more carers awaiting allocation. We will continue to develop</p>

		<p>and offer these opportunities in the foreseeable future additional lottery funding has been awarded which will fund the additional growth. It is important to note that there are legitimately estimated 130,000-200,000 carers in Derbyshire, some of whom may not be aware that they are carers, so it is extremely challenging to ensure that all carers know what support is available. Nevertheless, we will continue to ensure that we are supporting as many carers as possible. The DCA Young Carers service provides the opportunity for carers to transition to adult services, having support 24/7. The young carer's service is in year 2 and increasing carer awareness within education and health settings. Sharing the message of talking together to reduce the stigma some young carers feel and offering opportunities to reduce caring responsibilities.</p> <p>Carer support staff with a cohort of 35 carers share their experiences to year 3 nursing students at Derby University aiding their understanding of carers and their experience and knowledge</p> <p>We attend all living well clinics to meet with carers at the earliest point after diagnosis of dementia to offer information and advice about the range of support services available for carers to improve their caring journey, we have attended 30 living well groups these vary attendance per session of 4 - 12 carers.</p> <p>We also send out evaluation forms after every assessment and low-level intervention. These forms invite carers to give us feedback on how we can improve the services which we provide.</p>
4.	<p>To have more information about what carers are entitled to (i.e. carers rights), this should be in an easy to understand format</p>	<p>DCA aim to provide information on carer entitlements in a range of formats. Our website provides information on entitlements such as benefits, carer assessments, personal budgets and respite. This information is also available if carers have queries and wish to call DCA or visit our offices instead. In addition to this we are encouraging GP surgeries to sign up to the Carer's Pledge. This asks surgeries to ensure there is accessible, quality information (provided by DCA) available to carers. So far 45 surgeries have signed up to the pledge.</p>

		We are currently reviewing the pledge and will be working with the CCG to gain greater support to get practices to sign up.
5.	Raise awareness of the 'Carers in Derbyshire' website and ensure there is plenty of information about local services and support for carers	<p>We should thank DCC for their commitment to carers throughout Derbyshire evidenced by the resource they have made available</p> <p>It is vital this continues because of the contribution made by them to the health and social care system. This is not the case across the country and were it not so it would have a negative impact on health and social care.</p> <p>DCA actively promote the Carers in Derbyshire website. In fact, one of our board members, a carer himself had initial involvement in the design of the website. The team use this website with carers to view up to date information. It's one of many sources of valuable information for carers. We are aware from speaking to Carers that many do not access the internet or would choose to.</p>
6.	Work to create a 'one stop shop' for advice and signposting	<p>DCA aims to provide a single point of access for advice and signposting for Carers in Derbyshire. Derbyshire County Council have commissioned DCA as the lead provider of carer assessments and support services in the county. Adult Social Care, GPs and other voluntary organisations regularly refer carers to DCA for support. To this end, Adult Social Care have installed a liaison worker within the DCA office to ensure effective sharing of information and a smooth referral process. This way carers can easily be referred when they are identified during assessments of the cared-for. The health liaison team are also currently increasing our outreach to hospitals and GP surgeries. In the previous year we signposted carers on to relevant services, and provided information, advice and guidance</p> <p>Carers services are provided by many agencies both statutory and voluntary sector as well as private agencies. We would aim to liaise with all partner organisations to achieve best outcomes for Carers.</p>
7.	Ensure information around carers breaks and respite is readily available	DCA sends a newsletter 4 times per year outlining upcoming respite opportunities. This information is also made available on the DCA website and shared by all the staff team when they are working with carers. We will continue to consider new ways of raising awareness of the activities on offer. We

		have profiled carers in the last year with a royal visit to the DCA from Princess Anne. We've also taken opportunities for radio interviews and press releases.
8.	Promote local support groups and the benefits of peer support	DCA understand the value of peer support groups and we believe they are a fantastic way for carers to support one another and socialise. We currently support 16 peer support groups with 150 - 200 carers attending monthly in total. On the DCA website and in our newsletters a full list of details including contact details for each support group is available. We can also provide this information over the phone and in person at our offices and during events. We are developing new support groups in areas where previously none existed, constantly looking for new opportunities to increase these across the Derbyshire footprint
9.	Look to develop services/groups for carers and the cared for, that run side by side one another	It is important to note that the objective of the DCA is to provide support and respite opportunities for carers specifically. The aim of respite being that carers can take time away from their caring responsibilities. We understand however, that carers may want to take part in activities alongside their cared-for and we will consider the practicalities of such a service. We are keen to reduce perceived barriers and enable carers to access as much as possible whilst also getting the right venue and levels of support in place to ensure a safe environment and enjoyable activity contiguous to everyone's needs.
10.	Ensure that carers are always involved (where possible) in the care and treatment of the cared for.	This is key factor in all we do and a priority element in the carer's assessment and support plan. It's essential that carers have a voice and the value of that is critical in coproducing any documentations. The carers are the experts in their own caring role. DCA can signpost carers to formal advocacy services, so that their voices can be heard when important decisions are being made. The team linked with Derby university are using various mixed method approaches to evaluate and review the carers over the next 2 years , a carers reference panel will be consulted to maximise involvement in planning and shaping future carer services

	<p>“This report has highlighted many important issues for carers, many of which DCA have been advocating for over 30 years at the local and national level. To supplement this report and provide additional insight, DCA in collaboration with the University of Derby is soon to begin conducting its own evidence-based evaluation of the value of impact of carers’ services. This will look not only at the services provided by DCA, but also by other statutory and voluntary organisations. This evaluation will allow service providers to determine how to make best use of their limited resources to continue to meet the needs of carers in the future.”</p>
--	---

Derbyshire County Council (DCC): Derbyshire County Council welcomes the findings of the Healthwatch Carers Engagement Report. The content builds on what we have learned from carers through previous engagement and provides us with additional narrative which expands on the results of the 2018 Survey of Adult Carers in England (SACE). The findings will be used to inform the refresh of the Carers Strategy in 2019 and Derbyshire County Council are committed to working with key partners as part of Joined up Care Derbyshire to develop and improve support for carers through the strategy and multi-agency action planning.

Recommendation (What should happen now?)	Response
<p>1. Consider the option for carers to have face to face assessments and to ensure carers are signposted to support/relevant services following their assessment</p>	<p>Carers already have the option of a face to face assessment or review.</p> <p>Due to the increase in the number of carers referred for a carer assessment/review and the volume of carers awaiting a carer assessment, the commissioned carers service from Derbyshire Carers Association (DCA) is required to adopt a proportionate approach to assessment as laid out in the Care Act 2014 Statutory Guidance. The guidance recognises that assessments may, ‘where appropriate’ be carried out over the phone, in writing or online.</p> <p>DCC are aware nevertheless, that telephone assessments are unpopular with many carers and are working on ways to maximise capacity within the service whilst meeting the preferred methods of intervention.</p> <p>All carers are routinely signposted to relevant services and support as part of the support plan</p>

	<p>process following assessment. Access to good quality information, advice and signposting are crucial to carers and this is at the forefront of the Council's approach.</p> <p>Carer support can take many forms and does not automatically translate into funded services or a carer personal budget, rather this is one aspect of a range of support planning options. The Care Act 2014 introduced a national eligibility criteria for carers and this is used to determine support planning outcomes and in some situations, the provision of formal care and support to the person relying on care and support will meet the carer's eligible needs.</p> <p>Action</p> <p>DCC will work to ensure that carers are given clear options as to the method of assessment, to ensure assessment and review is carried out in a meaningful, personalised manner.</p> <p>DCC will continue to identify ways in which the commissioned service can meet the needs of an increasing number of carers and adopt a proportionate approach, without compromising practice and the offer of meaningful, effective support.</p> <p>DCC will examine how information can be improved to ensure carers are clear of their rights and the support that is available.</p>
<p>2. Ensure that the worker/professional undertaking the carer's assessments has good knowledge and understanding around caring for someone with mental health, learning disabilities, end of life etc.</p>	<p>Workers from both DCA and DCC are routinely provided with training to equip them with the knowledge and skills to support a range of carers.</p> <p>DCA have been working in close partnership with Derbyshire Hospices and Helen's Trust, in order to provide appropriate and timely support to carers who are supporting those at the end of life.</p> <p>DCC acknowledge that the support offer for mental health carers could be strengthened. Development work with mental health carers and partners is a priority for the commissioned service in 2019.</p> <p>Action:</p>

	<p>DCC will continue to ensure that all services provided or commissioned by the Council are responsive to a range of carers needs specifically any in relation to the needs of the person cared for., i.e. mental health, learning disability end of life.</p> <p>DCC and DCA will work alongside carers to identify how the service can be more accessible and responsive for mental health carers and how the mechanisms for feedback can be developed and refined.</p>
<p>3. To ensure carers receive the correct level of support to effectively care for their loved one and also look after their own health and well-being.</p>	<p>The day to day reality of carer’s lives mean that they regularly cross the boundaries of the health and social care system. It is recognised through the Carers Action Plan 2018-2020 and the NHS Long Term Plan, that it is essential that all carers are recognised and supported by public services and that raising awareness and best practice across the system is crucial to ensuring carers receive the correct level of support to care for their loved ones.</p> <p>DCC are committed to ensure that all carers in Derbyshire have access to the support, advice and information to best meet their needs and it is hoped that these national policy commitments will strengthen the local priorities in this respect.</p> <p>Adult Social Care and Health (ASCH) have also deployed a community care worker within the DCA carers centre, who acts as a conduit between DCC and DCA to ensure effective sharing of necessary information and facilitate coordinated, joined up responses to those families who also receive support through the Council and ASCH.</p> <p>Action:</p> <p>Improving the awareness and identification of carers will be one of the priorities within the refresh of the Carers Strategy and action planning will consider how best practice can be improved across the system through JUCD to ensure that all services respond proactively to support carers.</p> <p>DCC are also considering how to work with partners beyond health, social care and local government to raise awareness of caring among the wider population to build carer friendly</p>

	<p>communities and this will be one of the priorities of the revised Carer Strategy.</p> <p>The impact of caring on a carer’s health and wellbeing is well documented and the commissioned carer’s service will continue to strengthen partnerships to provide practical routes to wellbeing, increase carer resilience and promote the benefits of ‘self-care’ solutions.</p>
<p>4. To have more information about what carers are entitled to (i.e. carers rights), this should be in an easy to understand format.</p>	<p>Promoting carers rights is an ongoing area of development and importance across the system.</p> <p>Action:</p> <p>DCC will work closely with carers to ensure that information explaining their rights and entitlements is provided in an understandable format and to explore new ways in which these can effectively be communicated to them.</p> <p>The refresh of the carer’s strategy will enable DCC to work with a range of partners to consider how carer’s rights can be promoted and upheld throughout the health and social care system.</p> <p>The Carers in Derbyshire website and other carer publications which have been developed by DCC, will be reviewed to ensure there is clear, helpful information provided about carers rights.</p> <p>https://www.carersinderbyshire.org.uk/carers-rights</p>
<p>5. Raise awareness of the ‘Carers in Derbyshire’ website and ensure there is plenty of information about local services and support for carers</p>	<p>It is disappointing that many carers were not aware of the Carers in Derbyshire Carers in Derbyshire website Facebook Twitter and newsletter as these have been co-produced with carers and viewed as one of our recent successes in supporting carers based on the feedback we have received directly from carers and professionals.</p> <p>Action:</p> <p>DCC will request that a link to the Carers in Derbyshire portal is on all partner websites across the health and care system. Promotional merchandise has been developed and this will continue to be distributed widely.</p> <p>Carers are now routinely invited to sign up to the e-newsletter as part of their carer</p>

	<p>assessment and it is hoped that this will help to promote and share the website, Facebook and twitter throughout carer communities.</p>
<p>6. Work to create a ‘one stop shop’ for advice and signposting.</p>	<p>DCC recognise that obtaining the right information at the right time is a high-ranking and ongoing priority for all carers and a vital area of investment in effectively supporting carers.</p> <p>DCC have therefore commissioned a single point of access to provide information advice and guidance as part of the carers contract with DCA, so it is unfortunate that some carers are either not aware of this service or do not perceive this service to be a ‘one stop shop’ where they can find the information they need.</p> <p>Action:</p> <p>DCC will work with carers and DCA to consider how we can raise the profile of this vital service and ensure that carers use the service in order to obtain the information they need, when they need it.</p>
<p>7. Ensure information around carers breaks and respite is readily available.</p>	<p>DCC recognise that a break from caring is another high-ranking and ongoing priority for all carers and a vital area of investment in effectively supporting carers. It is widely understood how difficult it can be for some carers to accept their need for a break and this is often for a variety of complex reasons.</p> <p>DCC have commissioned a service from DCA which provides different opportunities for carers to take a break and provide information about accessing respite for loved ones. DCA issue almost 2000 carer personal budgets per year to enable carers to take a break from caring. DCC also provide breaks and respite for carers through the provision of support for the cared for person in line with the statutory duties outlined in the Care Act 2014.</p> <p>https://www.carersinderbyshire.org.uk/carers-respite-service</p> <p>Action:</p> <p>DCC will continue to work with carers, Council staff and DCA to ensure that carers have the right information and opportunities to access a break from caring.</p>

	<p>DCC is exploring new ways to provide breaks for carers, through technology, innovation and increasing the recognition of carers in local communities and the wider society.</p> <p>DCC will work with commercial partners and organisations who can offer free or discounted breaks to carers and continue to promote Timeswap as a support option for carers.</p>
<p>8. Promote local support groups and the benefits of peer support.</p>	<p>DCC recognise that peer support is a further high-ranking priority for many carers and a vital area of investment in effectively supporting carers, accepting that this can be difficult for some carers to access on a regular basis.</p> <p>DCC is committed to expand the diversity and range of peer support opportunities for carers across the county. This is a requirement of the commissioned service provided by Derbyshire Carers</p> <p>Action:</p> <p>DCC will carry out further engagement with carers to understand what peer support means to carers and consider how some of the barriers to accessing peer support can be removed for working carers, isolated carers and those who cannot easily leave the person depending on them.</p> <p>DCA have been exploring new ways to provide peer support for isolated and rural carers through the provision of phone-based peer support and the development of new support groups in partnership with pan-Derbyshire organisations.</p> <p>https://www.carersinderbyshire.org.uk/carers-directory</p>
<p>9. Look to develop services/groups for carers and the cared for, that run side by side one another.</p>	<p>DCC understand that some carers feel there is an assumption that they want to have a break away from the person who depends on them and as a result, there are limited peer support opportunities which also offer support to the cared for adult. We know it is important for many carers, to share the opportunity to get out with their loved one and many have increased peace of mind knowing the person they care for is close at hand.</p>

	<p>Action:</p> <p>DCC and DCA will continue to explore how they can strengthen partnership working with other services and organisations. For example, Dementia Support Service; Parkinson’s Society, in order to increase capacity and be able to provide support to the cared for person whilst keeping the focus on supporting the carer.</p>
<p>10. Ensure that carers are always involved (where possible) in the care and treatment of the cared for.</p>	<p>DCC recognise that carers are crucially important to how we plan and deliver health and social care in Derbyshire and how their collective contribution is not only vital in sustaining and improving the health and wellbeing of those they care for, but also strengthens the health and social care system across Derbyshire.</p> <p>DCC understand the importance to carers of feeling valued, respected and involved in the care and treatment of their loved ones.</p> <p>Action:</p> <p>Improving the recognition and respect of carers will be included as one of the priorities within the refresh of the Carers Strategy. Associated Action Plans will consider how best practice can be improved across the system through JUCD to ensure that carers feel they are listened to and their views are appropriately taken into account.</p>

10.0 Your feedback

Healthwatch Derbyshire is keen to find out how useful this report has been to you, and/or your organisation, in further developing your service. Please provide feedback as below, or via email.

1) I/we found this report to be: Useful / Not Useful

2) Why do you think this?

.....

.....

.....

3) Since reading this report:

a) We have already made the following changes:

.....
.....
.....

b) We will be making the following changes:

.....
.....
.....

Your name:

Organisation:

Email:

Tel No:

Please email to: helen@healthwatchderbyshire.co.uk or post to: Freepost HEALTHWATCH
DERBYSHIRE