



**‘Unpaid carers
in Wiltshire:
help in a crisis’**

An
independent voice
for the
people of Wiltshire

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Section 1: Background Information

What is this report about?

This report will tell you what unpaid carers said when they were asked about whether support services on offer were meeting their needs, and specifically what services would make the most positive impact to them when they require immediate support. This report has been put together to inform Wiltshire Council what carers have said is important so that they can take this into account when making decisions about future services.



Healthwatch Wiltshire is an independent organisation which has an important role in assessing the quality of health and social care services today and influencing the design of services for tomorrow.

The report covers engagement with a wide range of unpaid carers. This includes adult carers who are caring for another adult, parents who are caring for a child who has additional health needs, and young people (including children) who have a caring role. Whilst there were different views expressed the key messages from carers can be summarised as follows:

The Key Messages

1. Carers need help available, at the end of a 'phone, 24/7 for advice and a listening ear
2. Appropriate and timely respite support (including domiciliary care, sitting service, overnight) would be really valuable
3. Awareness about what is available is patchy. Information about services (and eligibility) must be accessible and well-advertised.
4. Training for carers would be welcomed (e.g. manual handling, dementia, mental health, addictions)
5. Appropriate emotional support (and peer support) and counselling would help carers to feel more supported and understood.
6. Agencies have a responsibility to work well together and 'join up' (especially important for parent carers). This includes taking responsibility for making referrals so that carers get the help they need.
7. Mental health is seen as a poor relation to physical health issues. Carers are concerned about levels of understanding, help and support for mental health
8. Services for the cared for person **must** be in place otherwise there is a negative impact on their unpaid carers.

What is Healthwatch Wiltshire (HWW)?

Healthwatch Wiltshire (HWW) is an independent local organisation which has an important statutory duty to speak up for local people on health and social care. You can find out more about HWW on our website: www.healthwatchwiltshire.co.uk.

What was the engagement project about?

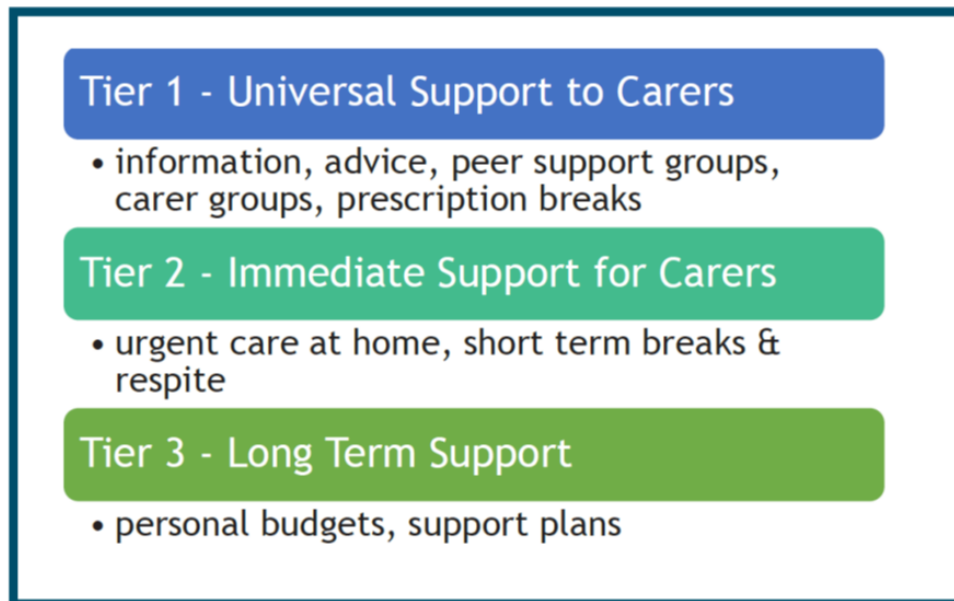
In response to the new duties which the Care Act 2014 introduces, Wiltshire Council has approved a new model of support for unpaid carers. Features of the act that are particularly relevant to carers are:

- An entitlement for every carer to have an assessment of their own needs
- An emphasis on prevention and well being
- A duty to provide people with information and advice about health and care services

The model seeks to deliver a wide range of universal support as well as specific immediate and long term support tailored to the carers needs. Carers were consulted on the model and broadly supported the approach. Wiltshire Council agreed that further engagement with carers should take place to ensure the right support is put in place. HWW agreed to independently facilitate this engagement as part of its work on the Care Act and Better Care Plan.



Given the new duties of the Care Act it is important that the services on offer are meeting the needs of carers. The Council want to particularly understand what services would make the most positive impact at 'tier 2'. This is to prevent crisis and provide speedy intervention without those services necessarily only being 'unlocked' through a full carers' assessment (at 'tier 3').



Section 2: What did we do?

The engagement project ran between late April and the end of June 2015. During this period there was a lot of activity to support the engagement process. Detailed information about the project can be found at the back of this report.

An information sheet, for carers, about the project and its aims was prepared and made available. The engagement was promoted in several ways including through social media. We used press releases to get the message out through local media. There was information available on websites including a dedicated page on Healthwatch Wiltshire's website which attracted 52 page views. The engagement was promoted in newsletters including Healthwatch Wiltshire's Spring Newsletter which was sent to 292 subscribers. We made local charities aware of the engagement project and invited them to help promote it.

Focus groups were held to engage with carers from a range of groups:

1. Parent carers
2. Young carers
3. Carers of people with mental ill health
4. Carers of people who misuse substances (i.e. alcohol and drugs)
5. Elderly carers of adults
6. Carers of people living with dementia
7. Adult carers of adults (including carers in work, carers from black and minority ethnic groups and carers in military communities).

"Experience has been that in a crisis there is no support and responsibility is put back on carers"

Carer in a meeting

5 focus groups were held around the county giving carers the opportunity to share their experiences of the caring role and answer specific questions designed to facilitate discussion. The questions were:

1. Have you (as the carer) ever needed help in a crisis? Did you feel you received appropriate help?
2. What do you consider to be crisis situation(s) that would require immediate support?
3. What sort of help do you think would support carers and the cared for person in a crisis situation? How could this best be provided?
4. What do you think is a reasonable process for getting immediate help?
5. Do you think that having crisis support available would give you the confidence to continue with your caring role (for longer)?
6. Is there anything else about your experience as a carer that you would like to share?



Overall 42 carers attended the 5 focus groups.

HWW wanted to be sure it was engaging with as many carers as possible from all the groups listed above. It felt, to effectively engage with young carers it would need to go out and talk to them in an environment in which they were comfortable and relaxed. Therefore, HWW attended activity sessions run by Spurgeons, the organisation who supports young carers in Wiltshire. 9 young carers spoke about their experiences.

Following the focus groups HWW reviewed what carers had told us so far and decided to produce an online survey which included some of the key messages and outcomes from the focus groups. The survey was shared widely throughout the local voluntary and community sector and advertised on the HWW website and social media pages. It was also available in hard copy with a freepost return envelope. There were 91 responses to the survey. The survey with results is attached at the back of this report. At the end of the survey people were invited to answer a 'free text' question - Is there anything else you would like to say about your caring role and crisis situations? 46 people responded to this question. Their comments are summarised later within this report.

HWW attended 9 other meetings and events in local communities including carer cafés, and memory groups. At all of the meetings and events we arranged or attended we invited people to complete the survey. We invited discussion and recorded what people told us.

HWW was pleased to be invited to attend the Carers Reference Group of the Wiltshire Safeguarding Adults Board which provided important information from carers from a safeguarding perspective. HWW also offered carers the opportunity for an individual interview - either 'face to face' or on the telephone. 12 people took up this option.

The engagement exercise was designed to provide Wiltshire Council with good quality information about what carers believe would best support them at 'tier 2' so that decisions can be taken on the type of services to put in place. The approach was designed to reach a wide range of carers using different engagement techniques. Whilst HWW led the exercise it was keen to work through specialist voluntary sector organisations where appropriate and possible. Such organisations were invited to engage with their members and service users and to submit the outcomes to HWW so that they could be included in this report.

Healthwatch Wiltshire knows from its experience of engagement projects that often people will share other information about their views or experiences. This additional information is included within this report and will be responded to separately.

“It is such a battle trying to keep him positive”

Carer of someone with mental ill health



Section 3: What did carers say?

Healthwatch Wiltshire has analysed all the responses to this engagement project, whether these were made through the survey, focus groups or more general outreach with carers.

1. Have you (as the carer) ever needed help in a crisis? Did you feel you received appropriate help?

Many carers said that they just coped with the majority of things that came up and wouldn't necessarily think to ask for support.

A number of carers talked about their experience of needing help in a crisis. The majority of these felt that they had not received appropriate help. Carers talked about contacting their GP, Wiltshire Council and the Mental Health Team in these instances and said that they were not given the help they needed. These carers reported that when they asked for help, the responsibility was pushed back on to them. A number of people said that the response they got was "What do you want me to do about it?" when asking for help in a crisis. This was felt to be not helpful in crisis situations as people didn't know what was available and the statement implied that that the person couldn't help. Several carers said that having asked for help in a crisis, they were told that someone would get in touch or visit but that this had not happened. A carer said that when he was extremely distressed he was contacted by the Mental Health crisis team and told someone would visit the next day. This had not happened and he had to follow up himself.

A few positive experiences of receiving help in a crisis were reported. One carer said they had contacted the Duty Social Work team when they were told last minute that their respite care was being cut short. They said that the duty social worker was 'brilliant' and sorted out the problem. Carers said that they felt the quality of response you got could vary according to who was on the end of the phone.

A number of carers said they had called 111 or 999 in a crisis situation that, for example, included the person they cared for falling and being unable to get up, or unexpected illness. These carers said that they had received a good response from this service and it was helpful.

A number of carers said that they had had a crisis and had not received the appropriate help because they hadn't known who to contact. These carers said that they had either managed things as best they could or asked friends, family members or neighbours for help. Some carers said that they found using their own informal support networks, was useful and appropriate in crisis situations, particularly in the short term. However other carers said specifically that they didn't want to have to ask friends and family for support. These carers said that they felt that this would negatively affect their relationships and could lead to their own, already limited, opportunities for socialising being adversely affected.

Carers felt that, looking back on crisis situations, that they probably understated the extent of the issue when asking for support. Reasons for this were that carers didn't like to admit that they were unable to cope and, in some cases, a fear that the support offered would be intrusive, or that the person they care for could be taken into care as a result of asking for help.

The fact that carers tend to understate the extent of the crisis should be taken into account by people responding to calls for support.

Some carers said that they were aware that, in a crisis, they lost their sense of logic because of the stress they were under, and they felt that having someone to listen and advise would be helpful.

Many carers said that crisis situations often happened at night or at the weekends, and they were not aware of who they could call out of office hours. They noted that many services offering support to carers were only available Monday - Friday, 9 - 5.

Most carers we spoke to, who had experienced a crisis situation, did not feel they received appropriate support. Carers did not have clear information about who to contact in a crisis situation. Many carers were not aware of any out of hours contact numbers. In a number of cases, when carers had asked for help in a crisis the response was not helpful. Carers need to know who to contact in a crisis and need to receive an appropriate response.



2. What do you consider to be crisis situation(s) that would require immediate support?

Carers talked about a number of crisis situations that they thought would require immediate support:

Carer illness, accident or breakdown

Having an accident or illness which meant they were not able to perform their caring role was a major concern for carers, and the most common reason they gave that might cause a crisis situation requiring immediate support. 49.3% of those who responded to the survey said that they had a crisis because their own health deteriorated. Carers gave examples of breaking bones, having severe stomach upsets and back problems. Carers worried about what would happen to the person they cared for if they suddenly had to go into hospital. Some carers said that having the carers emergency card gave them some reassurance but the importance of keeping this information up to date was noted. A numbers of carers weren't aware of this card but said they thought it would be helpful.

Having to go into hospital for treatment was highlighted as a particular difficulty for carers. One carer said that they had paid for an operation privately to avoid a lengthy hospital stay. Another carer said that they had discharged themselves from hospital following a stroke as they were so worried about the person they care for.

“Apart from calling my social worker and possibly squeezing my son into respite care for a night, there is very little in place for me. An agreed written plan would help me stop worrying what to do as I have been ill recently and just struggled on. I never feel completely rested....”
Carer from online survey

Health deterioration of the cared for person

Carers talked about crisis situations which occurred as a result of a change in the person they cared for.

These included examples of physical problems which meant that the person was unable to stand or walk. Several people reported that urinary tract infections had resulted in changes which made it very difficult to care for the person.

Carers of people with mental health issues said that a sudden deterioration or breakdown in the mental health of the person they care for led to crisis situations where they needed immediate advice and support about how to handle particular situations.

Carers of people with dementia talked about the difficulties of caring for people whose needs could vary day to day. A sudden deterioration and behavioural changes were examples of crisis situations that may need immediate support.

Family Bereavement

Some carers talked about their experiences of family bereavement and that, at these times, they needed immediate support, both in terms of replacement care for the person they cared for and emotional support for the person they cared for themselves.

Another family member needing support and/or care

A number of carers said that they would need immediate support in a crisis that involved someone else needing their support or care. Carers gave examples of being needed to care for other relatives following operations, illnesses, or to deal with stressful events. Some carers were involved in caring for two different people and said a crisis would occur because of competing needs between them.

One carer described how she had asked for respite care for her mother who had dementia, because she needed to travel abroad to support her sister who had just had a serious operation. This was not provided and she ended up having to take her mother with her, she described this situation as “so stressful” as it meant she was having to care for two people, including a person with dementia in an unfamiliar environment.

Breakdown of equipment or appliance

Carers talked about their experiences when there were problems with equipment or appliances that were needed for the person they care for. These included lifts breaking down, and faults with wheelchairs and frames, and the need for a special bed. Carers reported that currently there didn't seem to be any way of resolving these issues quickly and this could result in a crisis. They also said that being able to get the right equipment quickly may support them to deal with a crisis situation more easily and effectively.

Problems with existing support or care services for the person they care for

Carers said that problems with the care or support in place for the person they cared for could cause a crisis. Examples given included domiciliary care agencies, privately employed carers, and mental health services. Several people said that there were particular problems with appropriate services not being in place when people were discharged from hospital, and that this could cause a crisis. The main reason for this was because adequate arrangements for care and support at home had not been put in place and carers had to step in to either organise and/or provide this at the last minute.

“The on call social worker was brilliant and sorted it”

Carer South Wiltshire
Mencap



Emergency situation

Carers gave examples of emergency situations that could cause a crisis. These included fire and flood. Many carers said that they felt that crisis support would be very important in the event of such situations. Incidences of this occurring were rare but one or two carers did describe such a situation. It was said that these situations could result in safeguarding issues, particularly where the cared for person did not live with the carer and could be alone in such a situation. Carers highlighted that the emergency services responding to such emergencies needed to be alert to the fact that some people affected by these may need immediate support, as well as their carers and/or other services being informed.

A combination of events

Carers said that it was often not one single event that resulted in a crisis situation. Carers often said that whilst they were often able to manage some situations with their own resources, repeated occurrences or several situations occurring at once led to them being mentally and physically exhausted and, in these circumstances, immediate support was required.

Many carers said that a crisis situation occurred because they reached the point where they couldn't cope anymore. Some carers said that, at this point, they had often been asking for help for some time. Once they had got to the point where they felt they couldn't cope, they felt immediate support was needed.

Carers described a variety of crisis situations which they believed would require immediate support. Those most commonly reported were that carers own health deteriorated or that behavioural or physical health changes in the person they cared for meant they could no longer care for them. Although the responses to each crisis would need to be tailored to the carer and the particular crisis, it was felt that there are opportunities to plan some services that would help in common crisis situations.

3. What sort of help do you think would support carers and the cared for person in a crisis situation? How could this best be provided?

Carers said that it was really important that the response in a crisis situation was tailored and personalised to the individual carer. They gave a number of suggestions about what sort of things they thought would best support them and the person they cared for in a crisis situation.

Help 24/7

Many carers said that a helpline for carers would be extremely valuable. Carers said that in a crisis situation, they needed one point of contact available 24 hours a day. This was the most commonly supported idea from carers we spoke to in the focus groups and outreach. It was also the second top answer in our survey. Carers also suggested a number of things that would be important about a helpline for it to be effective. These are detailed in the following section about the process for getting help.

Carers told us that they didn't feel that this was available at the moment and, in general they were not aware of existing helpline numbers, with the exception of 111.

Someone to talk to about the experience of caring and for advice

Closely related to the idea of a helpline, many carers said that in a crisis situation, they really wanted to talk to someone who understood what it was like to be a carer. Many carers said that being able to talk to someone about their experiences, frustrations and difficulties in a crisis situation had been beneficial to them when it had been available. Some of these carers said that having a listening ear and someone to give advice, was enough in itself, to support them to manage a crisis situation. Carers who hadn't had this, or didn't have an empathetic response, said that this would have been useful. This was the top answer in our survey with 51.6 % of carers putting this in to the top four things that would be most helpful. Carers also gave suggestions of things that would be important about this service and these are included in the following section—question 4.

Respite care

Respite care was identified as something that would be essential in some crisis situations. This was particularly the case in a crisis that involved the carer having an accident or sudden illness, when carers said that respite may need to be made available very quickly. Many people talked about their difficulties accessing respite in a crisis situation and said that this had exacerbated the stress of their situation. In our survey 47.2% of carers put immediate respite care in the top four things that would be most helpful.

Respite was also thought to be something that would be useful to carers in situations when the health of the person they cared for deteriorated. Some carers cited examples where they felt that this not being provided had resulted in hospital admission or a permanent care placement which was perhaps unnecessary.

Short term domiciliary care

Some carers said that they would need replacement care in a crisis but that this would not be best provided in a residential care setting. This was particularly highlighted by some parent carers. These carers thought that care provided at home would be most useful to them in a crisis situation. This included care for the person they cared for and domestic help.



Many carers talked about the demands of carrying out all the day to day domestic tasks for themselves and the person they care for, in a crisis situation. In our focus and outreach groups some carers felt that some domestic help in these situations would be more effective as it would enable them to concentrate on their caring role. In our survey 32.3% of carers listed access to domiciliary care for up to 72 hours in the top four things that would be most helpful.

A counselling service for carers

Many carers said that they thought a counselling service for carers would be helpful in a crisis with 36.3% of our survey respondent's listing this in their top four useful things. A number of carers in our focus and outreach groups talked about their experience of having counselling in crisis situations. Almost all carers who had had counselling said that they had found it very helpful in managing and resolving a crisis situation. Carers said, specifically, that being able to talk about their emotions and frustrations, and being given advice about how to handle complex family situations was useful. This was particularly thought to be the case in crisis situations that involve bereavement and family breakdown.

An agreed written crisis plan

Many carers said that having an agreed plan about what would happen in a crisis would be useful. 32.9% of our survey respondent's listed this in their top four useful things. Lots of carers we talked to talked about having a Carers Emergency card, and that, in registering for this, they had provided information about the support that the person they cared for would need in the event of an emergency. Carers who didn't know about this card felt it would be useful. It was felt that this information was already a start in planning about what would be needed in a crisis situation which could be extended on.

Carers handbook or website

Carers talked about not knowing where to go for support or help. Many carers in our focus and outreach groups said that they had not received the help they needed in a crisis because they had no idea where to go when the crisis occurred. Often they said that they had later found out about services that would have been helpful. Carers said that information in a handbook or website where they could easily find the numbers they needed for support would be useful. 34% of our survey respondent's listed this in their top four useful things. Carers in our focus and outreach groups said that this information would need to be in one place, widely advertised and distributed to carers and that it should be brief and just concentrate on giving the most important numbers to call in situations. Examples given were 999, 111, Wiltshire Council Emergency out of hours number, Carers Support with a brief description of when to use each number.

Other

Some carers suggested other things that would help them in particular crisis situations. These were: a mentoring and linking service where carers could support each other, this might include advice, social support as well as practical help in a crisis, e.g. help with shopping; specific training for carers that may help them to cope in a crisis; speedy supply of equipment in an emergency and a one off payment that allowed carers to organise their own support in a crisis.

Carers suggested that a variety of services would be needed to support them in crisis situations. The ones they thought most important were help available on the telephone 24 hours a day, someone to talk to about the experience of caring and for advice, and respite care. Many carers were not aware of any 24 hour emergency numbers that currently operate. Carers often said that they had to get information from many different sources, and often didn't find out about things at the time they needed them.

4. What do you think is a reasonable process for getting immediate help?

Carers said that, most importantly, there should be one single point of contact that they could contact in a crisis situation. This needed to be a well-advertised phone number which went straight through to a person, rather than an automated system. Some carers suggested that it would be a good idea to make use of something existing to provide this. Wiltshire Council Out of Hours emergency Social Care numbers and the Medvivo responder service were given as examples of 24 hour lines that were currently operated.

Carers said that it was very important that the person who answered the phone was experienced in supporting carers. They felt it was important the person would be aware that carers often tend to understate the extent of the crisis. In general carers said that signposting them to contact other agencies was not helpful in a crisis situation. They felt it would be very important that the responder would be able to ‘take over’ and make referrals directly, and report back on the action they had taken. Carers mentioned that for this to happen, the responder would need to have the authority to allocate resources, for example, emergency respite care. Carers also said that it was important that the person on the end of the phone had the skills and understanding to be able to listen, empathise and give practical advice. They said that often, talking to an understanding person helped them to feel better and manage the immediate crisis situation more effectively.

We talked to carers about how quickly they felt it was reasonable for help to be put in place. Carers talked about some situations where support would need to be put in place extremely quickly, within hours. Examples of such situations were those when the main carer of a vulnerable person was involved in an accident and unable to care for them at this time. Carers highlighted that there are some situations when a crisis situation can mean that there are safeguarding risks, and that these would be increased if there was not a quick and appropriate response.



“I would like more groups where carer/cared for can meet. I would like to speak to someone urgently when I feel vulnerable, worried and isolated so they can reassure me”

Survey Response

However the carers we spoke to said that although there were some situations where it was very important that support was put in place immediately, they thought that these were a relatively small number.

Many carers said that they appreciated that it may not be possible to put support in place immediately in all crisis situations. In such situations carers said that it was very important that they were told what would be put in place and when, and that this happened. Many carers reported their experiences of being told that they would receive a phone call, visit or review and that this had not happened, and they were often unsure of who to go back to in order to follow this up

Carers gave many examples of resilience and being able to cope, in the short term, with some very challenging crisis situations. However, they said that this was less stressful, if they know that support was forthcoming. This was particularly the case with situations where carers became physically and/or mentally exhausted following a crisis and were requesting respite care for the person they cared for. Many carers said that they felt that they would be able to carry on, if they had a date when respite would be coming. Being put on an open ended waiting list for either a carers assessment or respite being available was not thought to be at all helpful in such situations. It was felt that the time that carers were able to wait for respite would vary according to individual circumstances. However many carers said they felt that they would be able to wait 1 - 2 weeks.

Carers talked about whether there should be a limit to how long crisis support should be offered. It was thought that if support was still needed several weeks after an event, then it was likely that it was an ongoing issue. In these cases carers thought that the carer and cared for person should be assessed with a view to long term support. It was recognised that Wiltshire Council has limited resources and would not be able to provide crisis support indefinitely.

In a crisis carers want a well-advertised, single point of contact, available 24 hours a day. The person on the end of the phone would need to be empathetic and understanding as well as have the ability and authority to directly organise support, if needed.



5. Do you think that having crisis support available would give you the confidence to continue with your caring role (for longer)?

The majority of carers said that knowing that there was crisis support available would give them confidence to continue with their caring role. They said that they didn't feel that this was the current situation. In particular carers said that having access to out of hours support, someone they could talk to for support and advice, availability of respite care, and knowing there would be an effective response to an emergency situation were all things that would give them confidence to care for longer. This was especially the case for carers who were caring for people whose condition was likely to deteriorate over time such as people living with dementia.

Some carers said that the thought of not having the right support available in a crisis situation, meant that they would not feel able to continue to provide care in challenging situations. It was felt that this could cause admissions to hospital or permanent care home placements that might be avoidable if people knew crisis support was in place.

A minority of carers said that they didn't feel that crisis support would affect their confidence. Two main reasons were given for this. The first was that some carers said that they already felt confident in their caring role. These carers cited existing support groups, training, and sharing information with other carers and having good family support, as having contributed to their confidence as a carer. The second was that some carers said that they just couldn't contemplate the idea of discontinuing their role as a carer. This view was expressed particularly by people who cared for a partner or spouse who had mental health problems.

Carers also highlighted that there was a lot of non-crisis support that would give them confidence to continue with caring. This is detailed in the next section of this report.

The majority of carers we spoke to said that having crisis support available would make them feel confident in their caring role. It was felt that an effective response in a crisis situation could enable the cared for person to remain in their own home, and the carer to continue in their role for longer. Carers who already felt confident said that having support from family and carer support groups contributed to their confidence.

“There is currently a gap when children's respite finishes. No provision currently in adult services for people with challenging behaviour /autism. We have not had respite for 8 months because of this and are in crisis. We have no back up in an emergency.”

Survey Response

6. Is there anything else about your experience as a carer that you would like to share?

Many carers talked about the importance of services being in place that could prevent a crisis occurring. These included services aimed at both the carer and the cared for person.

Carers told us that support groups were very important to them. Many carers talked about the value of structured groups and of sharing information and experiences with each other. A number of carers reported that, recently, there seemed to have been a shift towards these groups becoming more like social events and being run by volunteers. Some carers said that they thought this had resulted in dwindling numbers which reduced the impact of such groups. Some carers also said that they didn't feel comfortable attending such groups that were held in public space (for example, a hotel or pub) as they were feeling low and emotional. They wanted the opportunity to talk about difficult issues in a supportive and private space.

Carers talked about the value of training courses that would support them in their caring role. In particular manual handling and dementia care and information were mentioned. Carers said that many of them would need replacement care to enable them to attend training courses.

Carers talked about the importance of being able to have a break in enabling them to continue in their caring role and prevent them from becoming exhausted. Carers mentioned 'Sitting service', Respite care and Day Centres as being valuable. Many carers said that they thought more of these services would be valuable to them.

Lack of suitable respite care came up many times. Carer groups who particularly reported this were carers of people with dementia, carers of people with learning disabilities and parent carers. Some parent carers said that they would like to accompany their children on respite. Some carers of people with autism said that they didn't feel that respite away from home would be beneficial either to themselves or the cared for person.

Many carers said that if the right services were put in place for the person that they cared for, then this could prevent a crisis situation from occurring. These concerns were primarily about support and services directed at the cared for person, both in terms of health and social care. Carers gave examples of particular issues. These included delays with mental health services input, and quality issues with domiciliary care services. Parent carers talked about the

difficulties they encountered getting statements of special educational needs. Carers also talked about problems when the person they cared for transferred from Children's to Adult services. Some carers said that they were often not kept informed about services for the person they cared for and that 'confidentiality' was given as a reason for this. This was often not helpful and carers felt could lead to safeguarding risks, particularly where they were the primary carer for someone with a mental health issue.

Carers of people who are self-funding said that they often felt left entirely on their own to organise support and care. In general, these carers said that the person they cared for was assessed or reviewed. Many self-funders said that they understood and accepted that they had to pay for services but required advice and support on how best to arrange them.



Carers talked about a lack of empathy towards them when they asked for support. Some carers said that they felt that the reason for this was that some professionals had poor knowledge and understanding of what was available and didn't know how to help. Carers said that they didn't feel that their contribution was recognised by many professionals or the general public at large. They pointed out that they saved local authorities, and society in general, huge amounts of funding by being an unpaid carer. Some carers said that they felt that they were regarded as 'benefit scroungers', and felt insulted by this.

It was evident from our engagement that carers were not always aware of all the support that was available to them. Carers shared their knowledge at our groups for example, about Carers Assessments, The Carers Emergency Card, Short Break Scheme, Carers Prescriptions, Direct Payments, and Welfare benefits.

Carers felt that it was important that services were in place that could prevent a crisis. Carers felt that support groups and training for carers were particularly valuable. The majority of the feedback about these existing services was positive. Carers felt that respite care in terms of 'sitting' services, day centres and residential care homes were important in preventing things coming to crisis. Carers reported difficulties and delays accessing such services and felt that there should be more available. Carers highlighted the importance of health and social care services that are directed at the cared for person being in place, in order to help prevent a crisis situation occurring.



Section 4: Equalities

An equality analysis was carried out during the review of this engagement process. Because of the short timescales in which this project was undertaken HWW has not been able to engage effectively with some groups of carers including:

| |
|--|
| 1. Young carers |
| 2. Carers in work |
| 3. Carers from black and minority ethnic groups |
| 4. Carers in military communities |
| 5. Carers to people with substance misuse issues |

Engagement with carers from these groups will need further attention.

Section 5: What next?

This report will be shared with Wiltshire Council and NHS Wiltshire's Clinical Commissioning group to inform their future commissioning plans to ensure that the right services are in place to meet the needs of carers.

During the engagement process HWW collected people's views on many issues relating to the caring role. We will make sure that these issues are monitored and looked at separately. In particular carers told us about:

- The importance of professionals recognising the carer and the role they play in looking after their loved one and being involved in decisions about their care.
- The value of carers groups and the opportunity this generates to share knowledge and experiences.
- The importance of services for the cared for person being in place
- Difficulties experienced by carers accessing appropriate respite care
- A lack of information and support given to carers of people who are self-funders
- Carers not being aware of all the benefits and services available to them

The Carers Trust recently published its analysis of local Better Care Fund Plans and the implementation of the Care Act

(http://www.carers.org/sites/default/files/better_care_for_carers_final_0.pdf).

It recommends that Health and Wellbeing Boards need to carefully consider their plans to support carers so that they align with the Better Care Fund and the Care Act. It says, *‘This can be done by engaging with carers and their representatives and finding out what it is they need to help them continue caring and by making sure resources allocated to carers are ring-fenced. Only then will the Better Care Fund deliver better outcomes for carers’*.

Healthwatch Wiltshire’s work, for Wiltshire Council, helps to ensure that the voices of unpaid carers influence the commissioning of services.

Finally, thank you!


Carers told us that they appreciated Wiltshire Council, through Healthwatch Wiltshire, asking them what would help them cope in a crisis.

Healthwatch Wiltshire would like to thank everyone who took the time to contribute their views to this engagement project including local community groups and charities who gave us the chance to meet their service users and members.

- Carer Support Wiltshire
- Wiltshire Parent Carer Council
- Spurgeons
- Mencap South Wiltshire
- Alzheimer’s Support
- Alzheimer’s Society

We would also like to thank the research team at Wiltshire Council for its help with the questionnaire.

Healthwatch Wiltshire is always interested in finding out about your experiences and views on health and social care services. Please get in touch with us.



“Your Voice is
our Voice”

Appendix 1

Survey of unpaid carers in Wiltshire

On behalf of Wiltshire Council and NHS Wiltshire Clinical Commissioning Group, Healthwatch Wiltshire agreed to independently facilitate an engagement project looking for support for unpaid carers.

Given the new duties of the Care Act it is important that the services on offer are meeting the needs of carers.

This survey seeks the views of unpaid carers in Wiltshire and their experiences of being a carer and the help and advice they need in a crisis situation. The role of unpaid carers in Wiltshire is an essential one. Without the help of such carers the Council and its partners could not hope to cope with the thousands of people that are cared for everyday by their spouses, partners, family, neighbours and friends.

The focus of this survey is to find out 'what would support carers during a crisis in order to prevent carer breakdown', and seeks to understand whether the services on offer are meeting the needs of carers, and specifically what services would make the most positive impact for carers who require immediate support.

PLEASE TAKE JUST 5 MINUTES TO FILL OUT THIS SURVEY AND GIVE US YOUR VIEW

Appendix 1

About your caring role

(Percentages are the number of carers choosing each reply of those who answered the question)

1. What is the nature of your caring role? (please tick all that apply)

- 41 (45%) *I care for a spouse or partner*
- 25 (27.5%) *I care for a child*
- 28 (33%) *I care for another family member*
- 1 (1%) *I care for a neighbour or friend*

2. Roughly how many hours a week do you provide necessary care? (please tick one box only)

- 11 (12.4%) *up to 10 hours a week*
- 10 (11.2%) *11-20 hours a week*
- 11 (12.4%) *21-40 hours a week*
- 57 (64%) *Over 40 hours a week*

3. How long have you been a carer? (please tick one box only)

- 4 (4.4%) *Under a year*
- 17 (18.9%) *Between 1 and 3 years*
- 36 (40%) *Between 3 and 10 years*
- 33 (36.7%) *Over 10 years*

4. Do you receive any funding or funded services to help you in your caring? (please tick one box only)

- 45 (50%) *Yes*
- 45 (50%) *No*

5. If yes can you say what?

- 45 (100.0%)

Coping with caring

- 6. Have you ever had a crisis which meant that you didn't feel you could carry on in your caring role, even if this would have been only for a short time? (Please tick the situations you have experienced that meant you felt you couldn't carry on caring at the time.)**

8 (10.1%) *There was a bereavement in the family*
15 (18.9%) *The health of the person I care for deteriorated*
39 (49.4%) *My own health deteriorated*
17 (21.5%) *Another family member needed my support*
25 (31.6%) *It was impossible to cope with the behaviour of the one I care for*
10 (12.7%) *There were financial problems that needed resolving*
3 (3.8%) *There was an equipment and or appliance breakdown*
7 (8.9%) *It became physically impossible to move the person I care for*
32 (46.8%) *I became so tired I needed a proper break*
17 (21.5%) *Other*

- 7. If you said other to question 6 can you say what crisis you experienced?**

26 (100.0%)

- 8. If you experience a crisis that stops your caring, who would you turn to? This does not include a genuine emergency when you would call the emergency services. (please tick all that apply)**

20 (22.2%) *I wouldn't really know who to turn to*
28 (30.1%) *I would go to my Doctor*
29 (32.2%) *I would contact a carers support agency*
12 (13.3%) *I would contact the Council*
4 (4.4%) *I would contact a charity help line*
8 (8.9%) *I would contact a carers network*
4 (4.4%) *I would go on the internet*
52 (57.8%) *I would ask my family*
20 (22.2%) *I would ask my friends*

Services in a crisis

- 9. If you have had need to involve an agency, voluntary group, the Council or your Doctor when a crisis happened, how did you feel about the service you received? (please tick the statements that are most like how you felt)**

30 (36.1%) *I haven't needed to call on any services*
27 (32%) *I got some help which was really useful*
11 (13.3%) *I got some help but it took a long time*
7 (8.4%) *I got some help but it wasn't what I needed*
15 (18%) *I didn't get much help at all as no one was really interested*

- 10. If you said that you didn't get the help you needed can you say what agency or organisation this was?**

12 (100.0%)

Below is a list of services that carers have told us could be useful in an emergency. Looking carefully at the list we want to know which ones to explore first. To do this we have limited you to FOUR choices so we can establish which services would be most useful and seek to implement. We appreciate that all the services listed are important to people but this will allow us to prioritise.

11. If you have a crisis which FOUR of the following do you think would be most useful? (Please tick up to four boxes only)

- 47 (51.6%) *Someone to talk to who had experience of caring and knew how to advise me and put me in touch with services that might help*
- 30 (32.9%) *Having an agreed written plan which shows me what to do in a crisis*
- 31 (34%) *A carers handbook and or website so I could easily find the numbers and support I needed*
- 33 (36.3%) *A counselling service just for carers*
- 21(23%) *A mentoring service where there was a another carer who knew my situation and could advise me*
- 16 (17.5%) *Some specific training in my role to help me cope in a crisis*
- 5 (5.5%) *An emergency equipment store to replace things immediately if they break*
- 30 (32.9%) *Access to domiciliary care for up to 72 hours to help*
- 46 (50.5%) *A 24/7 help line dedicated for care emergencies*
- 43 (47.2%) *A respite care scheme available for immediate use rather than having to be booked in advance*
- 18 (19.7%) *A one off payment for me to use as I see best to help get over the crisis*
- 4 (4.4%) *Other please say*

Finally

12. Is there anything else you would like to say about your caring role and crisis situations?

46 (100.0%)

13. If you would like to receive a copy of the final report please leave your contact details, name and email address below.

41 (100.0%)

The results of this survey will be used by Healthwatch Wiltshire to prepare a report for the Council and its partners on what carers say about what would help them in a crisis. Healthwatch Wiltshire is the independent champion for local people on health and social care. If you would like to provide more information about your caring role then Healthwatch Wiltshire would like to hear from you.

Please contact 01225 434218 or email info@healthwatchwiltshire.co.uk

Website: <http://www.healthwatchwiltshire.co.uk/support-unpaid-carers>

Appendix 2

Who we spoke to in Focus Groups

| Location | Type of group | Carers | Professionals / other | Total number |
|--------------|----------------------------------|-----------|-----------------------|--------------|
| Chippenham | General | 8 | 1 | 9 |
| Melksham | Parents Carers | 11 | 3 | 14 |
| Melksham | Mental Health / Substance Misuse | 6 | 1 | 7 |
| Salisbury | General | 8 | 4 | 12 |
| Semington | General | 9 | 1 | 10 |
| Total | | 42 | 10 | 52 |

Meetings and events in community areas where we talked to people

| Location | Type of group | Carers | Professionals / other | Total number |
|----------------------|--|-----------|-----------------------|--------------|
| Lydiard Park Swindon | Young Carers | 6 | 2 | 8 |
| Shrewton | Young carers | 3 | 1 | 4 |
| Chippenham | Dementia Carers | 11 | 1 | 12 |
| Chippenham | Carers (Mental Health) | 3 | 1 | 4 |
| Salisbury | Dementia Carers | 20 | 1 | 21 |
| Salisbury | General | 5 | 1 | 6 |
| Warminster | General | 9 | 2 | 11 |
| Salisbury | Learning Disability Carers | 14 | 3 | 17 |
| Trowbridge | Carers Reference Group (Wiltshire Safeguarding Adults Board) | 9 | 3 | 12 |
| Total | | 80 | 15 | 95 |

Survey

| Type | Total number |
|--------------------------------|--------------|
| Surveys completed online | 33 |
| Surveys completed in hard copy | 58 |
| Total | 91 |

One to one interviews

| Type | Total number |
|----------------------|--------------|
| Email feedback | 1 |
| Telephone interviews | 6 |
| Total | 7 |

Promotion of the Engagement Project

| |
|---|
| Literature about the engagement project for distribution at focus groups, outreach events, and for members of the public and voluntary sector partners |
| Healthwatch Wiltshire Spring Newsletter (April) (292 subscribers) |
| Healthwatch Wiltshire May ebulletin (292 subscribers) |
| Dedicated Healthwatch Wiltshire webpage (52 unique visitors) |
| Details of engagement project included in monthly Healthwatch Wiltshire updates sent to 18 Wiltshire Area Boards (Amesbury, Bradford on Avon, Calne, Chippenham, Corsham, Devizes, Malmesbury, Marlborough, Melksham, Pewsey, Royal Wootton Bassett and Cricklade, Salisbury, South West Wiltshire, |
| Twitter promotions x 9 |
| X 2 Press Releases sent to Wiltshire media |

Why not get involved?

Visit our website: www.healthwatchwiltshire.co.uk

Follow us on Twitter: @HWWilts

Email us: info@healthwatchwiltshire.co.uk

Phone us: 01225 434218

Write to us: 20 Hampton Park West, Melksham,
SN12 6LH

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