

Emergency Schemes for Carers in Britain: Results of a National Survey

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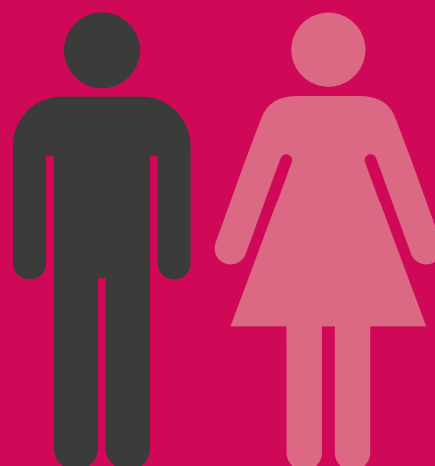
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Introduction

1.1 What are emergency schemes for carers?

Emergency schemes for family carers involve the establishment and delivery of an agreed plan of action and of alternative care in the (hopefully, unlikely) event of an emergency affecting a carer's ability to continue to provide care to someone who needs their support or supervision.

In these cases, the carer can ring the nominated scheme 24 hours a day, seven days a week, and speak to an operator who can then make alternative care arrangements in line with the plan drawn up between the carer and the scheme provider.

The number of emergency schemes in the UK is uncertain. In 2010, Carers UK found that out of 150 local authorities in England, only 30 had emergency schemes for carers. As of January 2011, the Carers UK website suggests that there may be 85 schemes operating in Britain, although our attempts to contact many of these led to no replies, and some may have ceased operating.

The National Survey reported here is the most up to date and most thorough attempt to identify the number and characteristics of emergency schemes in Britain today.

Carer profile 1: Using an emergency scheme – “it worked perfectly”

AY has been registered for the emergency scheme in Sunderland for two years. Not long after he registered he had cause to use the scheme as during a routine doctor's visit he was sent to hospital there and then. He had no chance to get home beforehand and so his daughter contacted the emergency scheme and alternative care was put into place immediately.

The scheme sent out care support workers to help his wife with a number of tasks she could not do herself, and provided care for her for the full length of time he was in hospital for which was two weeks. “The fact that someone was there provided me with peace of mind and reassurance.” AY told us that he felt that the best part of the emergency scheme was that it “fell straight into place” and someone was there straight away to look after his wife, “which was great.”

“Very, very good – for me it worked perfectly.”



What we already know – the existing literature

There are very few studies which have examined emergency schemes for family carers and those that have been conducted are generally small-scale or have some methodological limitations.

A few case studies of UK-based emergency schemes for carers have indicated how carers make use of such schemes and how they feel about them. For example, feedback on the Birmingham Carers Emergency Response Service (Salari, 2009) found that out of 1,000 carers signed up for the scheme, only 17 emergencies had been dealt with. This is not inconsistent with findings reported in this National Survey, which suggest that around four percent of registered carers are likely to use an emergency scheme in any one year (see **Table 5** later in this report).

The response to the Birmingham service (Salari, 2009) seemed to be very positive, with carers describing the service as “a lifeline” and one which had helped to alleviate stress for all individuals concerned. Moreover, the service had a positive impact on the carer’s health.

A study examining the well-being of carers in Wales also investigated contingency planning for adult carers (Seddon, Robinson, Tommis, Woods, Perry & Russell, 2009). Although there were emergency card schemes in place in Wales, carers did not feel that enough was done to provide support in the event of an emergency or crisis.

Research looking into urgent care services in England (Bridges, 2008) found that carers of older people accessing emergency care felt a great deal of satisfaction with this type and level of care, however carers also expressed some anxiety regarding their care recipient’s care. Some carers expressed fear that the cared for person would have difficulty accessing the emergency care they may require, and may have negative experiences of the care they receive (for example, a dread of acquired infections if they had to go into hospital to receive alternative care). This research did not focus on emergency schemes specifically set up for carers to help the care recipient in emergency cases, but it may indicate some of the factors which are important to take into account when setting up a scheme. For example, if the care recipient has to seek alternative care in a hospital environment, emergency schemes could make provision for a friend or relative to accompany them in order to alleviate some of the fears associated with hospital settings.

Dearden and Becker (1996) looked into one emergency scheme provided by a Crossroads Care scheme and found that while uptake of the scheme was low the scheme provided carers with peace of mind, and the costs of running it were low. This research pointed out the importance of details being kept up to date; otherwise problems could arise if third party care providers did not have the correct care information in an emergency situation.

A wide variety of factors can affect access to such schemes by carers. One study (Considine, Wellington, Kill, Smith, Gannon, Graco, Behm, Weiland, McCarthy & Corrie, 2009) found the following factors were key barriers to how carers and the care recipient accessed emergency care services:

- Delays in organisations providing the care
- Perceived waiting times
- Reluctance to seek emergency care schemes
- Trust in the knowledge and skills of staff involved in emergency care provision
- The interpersonal relationships of the staff and the planning strategies for the discharge of the patient.

This study (Considine, Wellington, Kill, Smith, Gannon, Graco, Behm, Weiland, McCarthy & Corrie, 2009) looked at a range of older, Australian carers and care recipients who had different experiences of emergency care and a variety of care needs. Whilst it may be difficult to generalise to a British population of carers as to the expectations of care and barriers to access, these factors can nonetheless be useful for any initial assessment as to whether these barriers exist within a UK context, and/or whether UK-based schemes have managed to remove or reduce these barriers to access. The evidence presented in the National Survey reported here shows that some of these barriers are being reported by some schemes in Britain today.

The small body of research conducted so far has also concentrated on qualitative evidence and the little that we do know about emergency schemes has generally been embedded in research of a wider scope, rather than being the focus of a specific enquiry. These limitations (methodological, research focus, sample size, etc) have led to emergency schemes in Britain being explored only at a peripheral level. Thus, very little is known about emergency schemes for carers in Britain.

The National Survey reported here is an attempt to provide a profile of what schemes exist and some of their broad characteristics, aims, strengths and weaknesses, so as to inform future service development and policy in this field. It would be reasonable to assume that the National Survey has captured in-depth data on more than 50% of emergency schemes in Britain today – a high response rate for this type of survey.



The National Survey – Results

3.1 Methodology and Scope

In order to investigate the prevalence and structure of emergency schemes currently available to carers in Britain, known workers involved in such schemes were invited to participate in an online National Survey, conducted by The University of Nottingham on behalf of The Princess Royal Trust for Carers. The questions for the survey were devised from a literature review of current research of emergency schemes; as well as from ideas put forward by carer leads, and an evidence-informed panel.

Scoping interviews with carers leads took an informal, telephone interview format which were conducted before the questionnaire was drawn up to inform this process. Eight carers leads from a variety of local authorities and Carers' Centres across Britain were asked open-ended questions pertaining to what is being provided currently for carers to use in emergency situations; how these operate; if they knew of any evaluation of the schemes; and how carers felt about them. It emerged that emergency schemes mainly operate at a local geographical level as opposed to national coverage; and schemes operate mostly on one of two levels of possible intensity:

Level 1

– the carer has a nominated person to help out during an emergency (for example, a family member or friend);

Level 2

– additionally to a nominated person, a support worker can step in to help with high need care recipients, often for 48-72 hours.

Some Level 1 and Level 2 schemes require carers to carry a card with their contact details on and also the details of the person they look after, with additional information about who should be contacted in an emergency. Someone finding the card would then be alerted to the need for action and would have the information required to activate a pre-planned emergency scheme.

Some other schemes (although none are reported in this National Survey) operate a card system only. This is where carers are given a card on which their details are written in order to notify someone that they are a carer and to raise the alarm if they were in an emergency situation. However, the details on the card are not linked to a contact centre or to a pre-emptive emergency plan.

This National Survey reported here focuses on Level 1 and Level 2-type services – what we would consider to be emergency planning and intervention schemes.

The National Survey reported here was concerned to find out:

- How emergency schemes work,
- How many people are registered with schemes, and how many people had actually used them in the past,
- The aims and objectives of schemes, and if these had been met,
- The weaknesses and advantages of schemes.

A copy of the survey instrument can be found in the Appendix. The survey was put online as a straight-forward web survey, hosted by **www.surveymonkey.com** and went live in March 2009. The questions in the survey were open-ended, allowing respondents to answer in as much detail as they wished. Emergency schemes were found by approaching local authorities and carers' organisations and asking if they were running an emergency scheme, as well as the Carers UK list of emergency schemes, and by approaching any organisation which suggested that they ran an emergency scheme (for example, the British Red Cross). The researchers also invited known schemes to email the questionnaire link to other schemes that they were aware of. A database of schemes was kept, and emergency schemes were emailed a link to this survey and asked to fill it in. The database was updated when responses came in, and reminders were sent out three times to ensure that we received as many responses as possible.

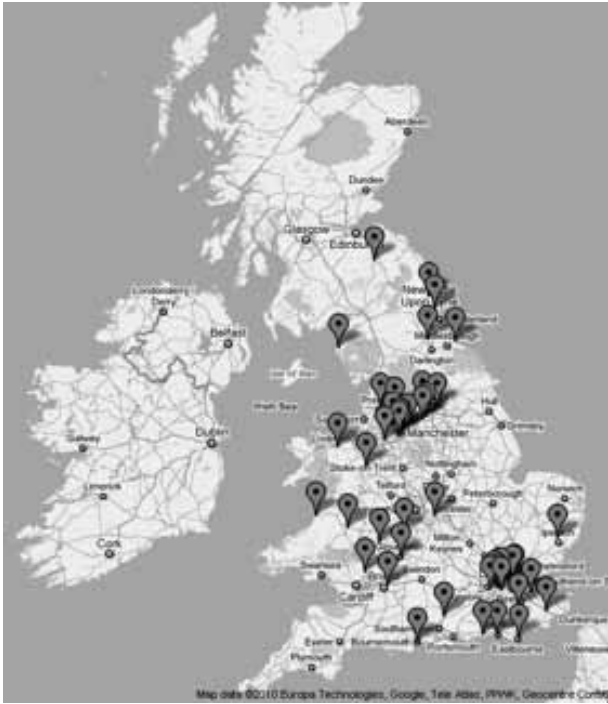
The results of the survey were collated, analysed and are reported below. As the responses collected were free text, a thematic analysis was undertaken, whereby the results of each question were read thoroughly and themes were extracted from what the schemes were telling us. Categories were devised from the responses given, and for each question all responses were categorised in order to quantify the frequency of responses. As the questions were open-ended, respondents were allowed to give as much detail as they wanted to, or in some cases, none at all. Some schemes fell into more than one category for some questions, which explains why in the results some of the numbers do not add up to the number of responses.

Quotations provided in the **narrative** and in boxed **Case studies** are from the workers who completed the survey about their particular scheme.

Boxed **Carer profiles** report ten telephone interviews that were conducted for this survey, of carers who are registered or who have used emergency schemes in the last couple of years.

A **Directory** of all of the schemes who completed the survey is also given at the end of this report, as is the **Survey questionnaire** that was used to capture the data.

Forty-eight full and detailed responses were collected, covering **49** schemes in total across Britain. The Carers UK list of emergency schemes lists 82 schemes in the UK; of these, 36 responded in detail to the National Survey, and we received thirteen responses from other schemes that were not listed. All of the schemes from the Carers UK site were contacted to see if they were still operational; 31 of the schemes were still running but did not complete the National Survey; 3 of the schemes were no longer running; and we were unable to contact 12 of the schemes despite repeated efforts to call them on the contact details available. We must assume that these schemes are also not operational. If they are operational, carers facing an emergency or crisis would also not be able to contact them. **This suggests that our response rate for the National Survey is high, with the projects reported here likely to represent well over 50% of emergency schemes in Britain today.**

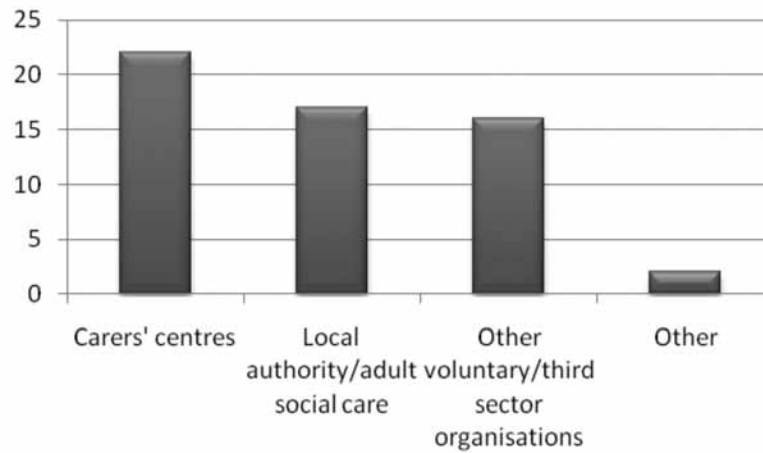


The map above shows the distribution of schemes that answered, and the table below shows how many schemes answered in various areas of Great Britain:

Scotland	1
Wales	5
North	2
North West	9
North East	7
Central	3
South West	3
South East	8
London	7

3.2 Who provides the schemes and who finances them?

Graph 1 shows the nature of the organisations running these schemes. The majority are provided by Carers' Centres (n=22) or by third sector organisations (n=16). Seventeen schemes are provided by local authorities or adult social care departments.



Graph 1: Organisations providing an emergency scheme for carers

Whilst the majority of schemes are *provided* by third sector organisations, the *financing* for most schemes comes largely from local authorities. The majority of emergency schemes reported that the funding to operate their facility came from the relevant local authority (83% of all schemes).

Eleven percent of schemes reported that funds came from a joint source; for example between the Primary Care Trust, local authority or third sector organisations. Only one scheme is funded by the Primary Care Trust solely, and only one receives all funding from a third sector organisation.

To what extent are the costs of providing emergency schemes transferred on to carers themselves through charges? The overwhelming majority of schemes stated that there is no charge imposed on the carer for registering or for accessing the emergency scheme. Only one scheme levied a charge: “The charge is for the centre to place the details on Carecall. Eight pounds per person after the initial £10 charge”.

Carer profile 2: “On top of that, there was no charge”

MJ is registered with the Red Cross emergency scheme in Northumberland and has a card stating that he is a carer for emergency situations. “When I’ve had to get to hospital quickly – the Red Cross have supplied transport. And when I’ve had to leave my wife quickly the Red Cross have supplied people to sit with her in several situations”. Two people are provided and sit with his wife for half a day in the event of care needing to be provided quickly. **MJ** said that the best thing was “the provision of someone to be with my wife with as little as 24 hours notice”. He rated the scheme as “pretty good. The Red Cross have stepped into the breach more than anyone else has”. This carer was unaware of the service for a long time and said that it was pure chance that he found out about the scheme as they do not appear to advertise it.

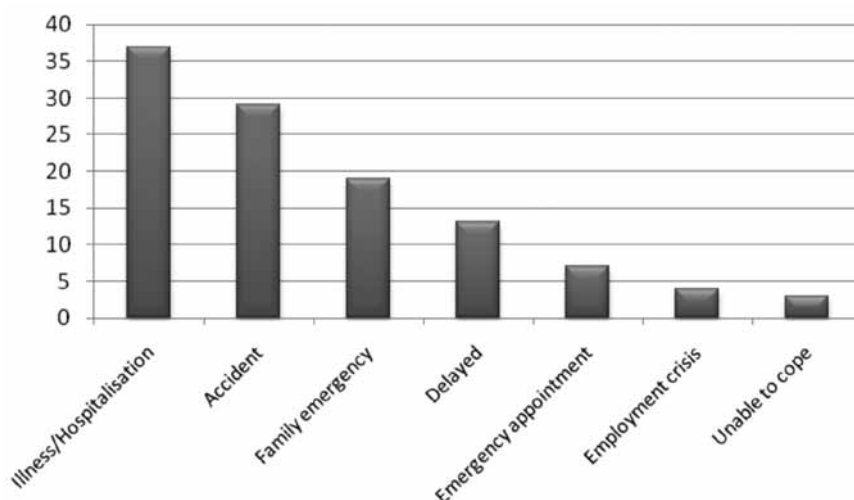
“It worked so easily and quickly, I was so surprised. And on top of that, there was no charge.”

3.3 What counts as an ‘emergency’?

A range of situations were cited by schemes that would activate the emergency plan and warrant the use of a scheme:

- **Thirty-seven** schemes responded that **sudden illness** or **hospitalisation** of the carer would constitute an emergency.
- **Twenty-nine** schemes stated that the carer having an **accident** would lead to the implementation of the emergency scheme.
- For **nineteen** schemes, a **family emergency**, such as **illness** or the **death** or **funeral** of a family member would be situations that would activate the emergency plan: *“The carer does not necessarily have to be ill or totally prevented from caring”*.
- Another emergency situation would be that the carer was **delayed** in returning to their cared for person, for example **being stuck in traffic** (13 schemes cited this).
- Some of the schemes (seven) cited an **emergency appointment** or urgent **last minute appointment** as an emergency.
- **Four** schemes cited an **employment crisis** as an emergency that would activate the plan.
- **Three** schemes said they would help if the carer was **not able to cope** or **not able to fulfil their caring role**; including one scheme that gave the example that if a carer’s washing machine was to fail, they would respond with the provision of funds to replace this if it was urgently needed for them to provide necessary care.

Graph 2 shows the frequency of responses. Please note, some schemes cited more than one reason as to what they would count as an emergency, explaining why there are more responses than schemes.



Graph 2: What counts as an emergency?

Case study 1: Types of emergencies

→ **EXAMPLE 1**

“A carer we provide a breaks service to was taken ill while we were with him. The care support worker phoned the GP as the carer was vomiting and was obviously unwell. The GP called an ambulance as the carer has an aneurysm and he was admitted to hospital for two days. We cared for his wife who has Parkinson’s and dementia. She cannot be left alone as she is unable to self care, prepare food or remember to take her medication. We provide care 24 hours a day seven days a week care until his return home. This gave him peace of mind that his wife was being cared for at home by staff she knew and prevented her from being admitted short term to residential care which would have distressed her due to her dementia. There are no other family members or friends available to support this elderly couple.”

→ **EXAMPLE 2**

“A carer was able to spend some time with her dying brother and have replacement care provided for her disabled partner in the home.”

→ **EXAMPLE 3**

“A couple, one of whom is virtually bed fast. The carer and the cared for go down with food poisoning, and the carer can no longer look after his wife. Contacted the scheme and staff went straight out, made sure that fluids were made available for both of them, contacted the GP and stayed until the GP had visited. Then went back to the property at regular intervals until their son was able to get from Yorkshire to provide support (approximately 24 hours).”

3.4 Aims of emergency schemes

There were eight main aims described by schemes, as shown in **Table 1**.

Aims of the scheme		Number of schemes identifying this aim
1.	Provide peace of mind or reassurance for carer	37
2.	Provide alternative care in the event of an emergency	30
3.	Reduce stress of the caring role	6
4.	Provide care in the home	4
5.	Prevent the breakdown of care	2
6.	Reduce inappropriate care admissions or hospital admissions	2
7.	Recognise the roles of carers	2
8.	Ensure carers are registered and involved in the scheme	1

Table 1: The aims of emergency schemes. (Schemes could identify multiple aims)

The two dominant aims cited by schemes were to (1) provide peace of mind and reassurance for the carer and (2) to provide alternative care in the event of an emergency or crisis. **Carer profile 3** provides illustrations from three separate carers about how being registered for a scheme provides them with this peace of mind and reassurance.

“To give peace of mind and reassurance to carers and increase confidence that will allow them the freedom to maximise life on a daily basis”.

Carer profile 3: Carers who spoke about peace of mind and reassurance

KC has been registered with the emergency scheme in Powys for 18 months, however she has not had a situation where she has had to use it. She had never heard of it until someone at the Carers' Centre told her about it, and finds it "very reassuring... I know contact will be made with the people nominated who will know what to do".

"I provide care 24 hours a day seven days a week, it worries me that if I'm out somewhere and my cared for isn't with me, if I had an accident someone will know to check on them."

TM has been registered with a scheme for 18 months, however he too has had no need to use it in that time. He carries the card with him at all times and wears a talisman around his neck so that medics or other people dealing with him in an emergency will know that he is a carer and be able to help. He was informed by a care support worker about the scheme, and is very happy with it – "I'm reluctant to leave my wife, but it gives me peace of mind that she would be looked after and not left on her own".

LR has been registered with a scheme for 18 months, but also has not had a need to use it. She sees it more from the point of view that if she was incapacitated, medics would find the card and know there is someone who needs to be cared for.

"It gives me extra peace of mind. Should something happen to me, they'll be on the case quicker."

Other, less cited aims included: reducing the stress associated with the caring role, providing home-based care, and preventing the breakdown of care.

3.5 Who can use the schemes?

The majority of schemes (44%) were aimed at all carers:

"The scheme is open to all carers and there are no limitations on who can join".

However, 35% of the schemes were aimed at carers in a particular area. A few of the schemes were more specific as to which carers could register and use their service; for example carers of individuals with specific conditions (in this sample, MS and dementia), or carers providing care to adults or children only (see **Table 2**).

Who can use the scheme	Number of schemes
All carers	21
Carers within specified area	17
Carers caring for adults	4
Adult carers	3
Carers caring for someone with particular care needs	2
Carers caring for children only	1

Table 2: Who can use the scheme?

While there is considerable variation between schemes in who can use their facilities (**Table 2**), there is also wide variation in the number of carers who actually register to use emergency schemes (**Table 3**). Just under half the schemes (n=22) have 400 or less people registered to use them. On average, each scheme has 558 carers registered for their emergency facility but this average obscures the wide variation between schemes. So, the lowest number of people registered for one scheme was 20 carers, and the highest was 2,500 carers, as that scheme is available to all carers without needing to register.

Number of people registered	Number of schemes	% of schemes
0-200	14	29.17
201-400	8	16.67
401-600	8	16.67
601-800	3	6.25
801-1000	2	4.17
1001+	6	12.50
N/a	7	14.58

Table 3: Amount of people registered for emergency schemes

On average, 4.2 people put emergency plans into action in each scheme in the three months prior to the survey being completed (**Table 4**); unfortunately, many schemes (14) were unaware of how many carers had used the scheme.

Number of people using the scheme	Number of schemes	% of schemes
0	13	27.08
1-2	12	25.00
3-10	5	10.42
11-20	3	6.25
21-30	0	0.00
31+	1	2.08
N/a	14	29.17

Table 4: Number of people using schemes in the past three months

The numbers of carers that used each scheme were then compared to the numbers of carers registered for each scheme (**Table 5**). It was found that on average, 0.86% of registered users in each scheme had used the scheme in an emergency in the past three months. If that pattern of use within the last three months was broadly similar throughout the year, it might suggest that up to four percent of registered carers are likely to use an emergency scheme in any one year.

% of registered users using the scheme	Number of schemes
0%	16
0.5-1%	11
2-3%	5
4-5%	0
5-6%	1
N/a	15

Table 5: Percentage of registered users of each scheme using scheme three months prior to the scheme completing the survey

3.6 Who makes an assessment of the emergency situation?

Three quarters of the schemes (32 schemes) conducted an individual assessment of the emergency situation when help is requested. This assessment, in theory at least, is important in determining the kind of help that might be provided in particular emergency situations. The National Survey was interested to know *who* conducts this initial assessment.

One third (35%) of these schemes completed an assessment through the **local authority** providing or supporting the scheme, and this may be the emergency duty team, social workers or the emergency duty team. For 19% of the schemes, the assessment was conducted by the **contact centre** staff upon receiving a call requesting care. One fifth (19%) of the schemes would use the **provider of the care** to do the assessment, and two schemes reported that it would be done by the first person who arrived to support the cared for person.

In 16% of cases, the assessment would be done by a contact at the **organisation** running the scheme, which could be the scheme's administrator or manager, or a receiving officer for example. Two schemes of the 32 completing assessments reported that two assessments would be completed for every situation; one conducted a social services assessment, **followed by** an assessment by the organisation running the scheme; and another would first collect the contact centre's assessment, and then conduct one through social services. Whether or not assessments translate themselves into actual interventions would be a valuable follow-up area of research.

3.7 Who actually provides the alternative care?

Thirty-eight percent of the schemes stated that the **emergency contact** given when the carer first registered would be contacted in an emergency or crisis situation, and if the nominated person was unavailable to help, the care would then be carried out by **a relevant care agency** or **voluntary organisation**.

Twenty-three percent of schemes reported that **friends** or **family** would be contacted to provide the care in an emergency situation, and 26% of the schemes said they arrange alternative care directly through a **care agency** or a **designated care worker** or **social services**.

Thirteen percent of schemes cited that it depends on the plan given, or that there is no single service that would provide the care.

3.8 Where is the emergency care provided?

Most schemes (77%) stated that the intention was to provide the emergency care in the carer's or cared for **person's own home**:

“Wherever is most appropriate – in the home is the preferred environment for all, particularly the person being cared for”.

Case study 2 provides illustrations from carers' workers of the types of emergency care that can be provided in the home.

Twenty-six percent of schemes stated that where the care is provided will depend on what is set out in the carer's emergency plan, and it is dependent on what is most appropriate at the time, and is determined by the needs of the cared for person.

Case study 2: Emergency care in the home

→ **EXAMPLE 1**

“A carer looks after wife with advanced dementia. He had an emergency hospital appointment and a home care worker moved in to the house between 7.30am-5.00pm. He was thrilled with the service and felt more at ease at the hospital.”

→ **EXAMPLE 2**

“A carer was suddenly taken into hospital due to breathing problems. The cared for was quadriplegic and unable to take care of herself. She rang the emergency number and we were there within one hour. We liaised with the hospital to give her peace of mind her husband was ok and stayed with her until he was discharged from hospital nine hours later.”

→ **EXAMPLE 3**

“One carer presented in A and E. Care Call, the carer’s next of kin and emergency contacts were contacted. No one was available to help. The social work team was contacted however they could not help immediately. The person was diabetic and needed a meal for tea. This was during office hours for Red Cross, and a colleague went and cooked the cared for a meal. The social work team was then able to provide care until the carer recovered.”

However, two schemes reported that if social services were involved in carrying out the emergency plan, there is a likelihood that the care would be provided in a residential setting (**Case study 3**).

Case study 3: Emergency care in residential settings

→ **EXAMPLE 1**

“The carer collapses; his wife has dementia. Contacting the call centre put the emergency situation into place and social services placed the lady with dementia into a nursing home whilst husband recovered in hospital.”

→ **EXAMPLE 2**

“We had a lady who went out to the flu clinic for her flu jab and on the way back she fell and broke her hip. The ambulance was called and a call was put through to our emergency line. This was picked up and dealt with by the social worker supporting the cared for person and emergency residential respite was arranged for the cared for person until the carer was able to return home.”

→ **EXAMPLE 3**

“A carer looks after husband who has arthritis and dementia and attends day service two times per week and rolling respite. She went shopping whilst he was at day centre. She tripped, hit her head and passed out; she came round in hospital. The hospital had found her card and had put plans in place for her husband to have residential care. She was in hospital for a week and she didn’t have to worry, as she knew husband was being looked after properly.”

3.9 How much support can be provided?

- **Four** schemes only provide care for a small number of hours, **up to half a day** in total.
- **Ten** schemes would provide from 24 hours **up to 48 hours** of alternative care to the cared for person.
- **Thirteen** schemes would provide between **48 and 72 hours** of care.
- **One** scheme, however, stated that it would provide care for **up to six weeks**.

The upper limit of 72 hours was largely reported to be provided if the emergency plan needed to be put into place over weekends or bank holidays.

Two schemes operated on a more financial rather than 'time' basis. One of these provided 48 hours of care and then a care and financial assessment was completed to establish the need and financial cost of continuing care; and the second scheme provided care up until £500 was spent in care costs.

Ten schemes provided care on the basis of who is providing the care, how long the care is needed for, and the reasons for the situation occurring. Six schemes were unable to answer this question.

Case study 4 provides some illustrations of the duration of support provided.

Case study 4: Amounts of emergency care provided

→ EXAMPLE 1

“A carer was sectioned under the Mental Health Act on a Friday just before the weekend. The carers’ team was notified and the contingency plan was activated. In this case the contingency plan was for the service user’s granddaughter and neighbour to provide emergency support. This arrangement was confirmed as being in place and when the plan was reviewed after 48 hours, the carer had been discharged and was able to resume her caring duties. In this case the contingency plan meant that interim arrangements could be put in place with minimum disruption to the service user. It also meant the most appropriate people were contacted rather than at the time of the emergency trying to determine which family member to contact.”

→ EXAMPLE 2

“A pregnant lone carer of a nine year old disabled child and his sister aged 12 called the emergency contact number at 2am as labour had started. The child’s personal assistant was contacted but had already been called by mum and was already at the home. As the personal assistant was in work the following day, the care agency were contacted and attended within two hours. Mum was admitted to hospital and the care agency remained in the home for the next three days until mum and baby returned home. Seventy-two hours was funded from the emergency budget, the remainder arranged by the allocated worker for the child. Both children were subject to the least disruption possible and continued their normal routine as much as possible. Previous to the call out, and at the time of completing the plan, agency staff had received training relevant to the child’s needs e.g. feeding, administering medication etc.”

3.10 Do schemes ‘evaluate’ their work?

Eleven schemes had either not been used at all at the time of the National Survey or had not been collecting any evidence of meeting their objectives or evaluating their interventions. Two of these schemes had not provided any emergency support to carers yet.

The remaining schemes had collected some evidence, but to varying degrees of sophistication or robustness, from *intuitive reasoning* through to *informal feedback* from carers through to *formal evaluation*:

→ **Eight** schemes responded **intuitively** that their scheme was operating as it was meant to, and working well, and that this – in their judgement – demonstrated that they had met their objectives. Three of these schemes reported that the good demand for their scheme showed they were operating well: “*The demand for the Emergency Card has remained incredibly high throughout, and carers are consistently signing up for the service*”.

- **Nineteen** schemes had received **feedback on an informal basis** from carers, either once they had accessed the scheme in the event of an emergency, or they had told the organisation that it was reassuring and gave them “peace of mind” that the plan was in place: “Carers [who] have taken up the scheme have stated that they feel a sense of security that if they are out and something happens to them there is support for the cared for who will know exactly what to do for them”.
- **Nine** schemes had carried out a more **formal evaluation**, either by using monitoring forms, or conducting written or verbal surveys with carers who had used the scheme. Only two of these made the outcomes of their evaluations available. One evaluation concerned an Emergency Card scheme for carers rather than a full emergency care scheme (Powys Carers’ Service, 2011). Fifty six carers completed a short evaluation and their feedback strongly reflected the themes of ‘peace of mind’ and the importance of this reassurance in supporting carers, and the need for wider awareness of schemes such as this. Another fifty carers completed a survey for Wandsworth Carers’ Centre (2010). Other than the benefits of the short-term care that would be provided in the event of an emergency, the main finding, again, was the peace of mind that carers gained from knowing that they were registered for an emergency scheme. Registering with the scheme had encouraged carers to talk about planning for emergencies with family and friends, and over half of the carers registered felt more independent and able to get ‘out and about’ due to the scheme. Four out of five carers also reported that they felt more confident that the person they cared for would receive the support they needed in the event of an emergency.

Perhaps there is a lack of formal evaluation because schemes are relatively new?

Table 6 shows how long these schemes have been operating. On average, the schemes have been running for three years. The longest running scheme had been running for 12 years at the time of data collection, and the shortest had been running for just one month.

Length of time running	Number of schemes	Percent
<1 year	5	10.20
1-2 years	31	63.27
3-4 years	2	4.08
>5 years	8	16.33
N/a	3	6.12

Table 6: Length of time schemes have been operating

3.11 Barriers and obstacles to carers accessing help

Thirteen schemes responded that they were **unaware of any barriers** to carers accessing help from their scheme.

However, other respondents offered a range of problems that they had encountered or expected to encounter which affected access. The two main issues that were identified by schemes related to carers **not being aware** of the scheme, and **problems with the**

provision of care. For example, **nine** schemes reported that there were a number of difficulties with carers not being aware of their scheme and that publicising the scheme can be confounded by financial constraints. One of these schemes also commented that professionals may not know to refer carers to register or apply for help: *“The only barrier evident is if [carers] do not actually know about the scheme”*.

Seven schemes expressed concern that some carers **would not have friends or family who would be able to take over** their role in the event of an emergency: *“A carer might not have any neighbours, relatives, friends to nominate”*. There can also be an associated issue if any nominated person **could not be contacted** when needed; and also with the **availability of emergency staffing** in the organisation being used to provide interim care.

Five respondents stated that carers often do not, or **do not want to consider planning** for an emergency, or **do not feel that the scheme is relevant** to them (see **Carer profile 4**, next page).

Three responses indicated that there was an issue of **identifying carers** to publicise the emergency schemes to; many carers do not consider themselves carers, and many do not access the services that would be promoting relevant emergency schemes.

There was also an issue highlighted by **three** schemes with regards to **limited resources or funding** within the organisation providing the emergency scheme, and therefore not being able to process the numbers of carers needing the service, or being able to advertise the scheme to its full potential.

A further scheme identified barriers related to **bureaucracy**. For example, the amount of paperwork can be overwhelming and burdening, and another scheme stated that not being able to apply for the facility over the internet could be an obstacle to access.

Carer profile 4: Lack of knowledge and keeping up to date

SB was prompted to register for the emergency scheme in Wandsworth after he had been in an accident, but had not had cause to use it but he finds it “reassuring to know it’s there”. He found out about the scheme through the Carers’ Centre. **SB** mentioned that the scheme seems to be well advertised, being promoted through the local authority and GP surgeries as well as through specific carer sources. However, he thought that many carers may not join as they don’t think they need to, or they do not understand the process and what the scheme involves.

SB perceived the main negative of the scheme to be the reliance on the information to be up to date, as knowing the scheme was there may make the carer complacent and those involved have to make sure the information is up to date to ensure the emergency plan can be delivered.

3.12 Strengths and advantages of emergency schemes

Most schemes primarily responded that the strengths of their emergency plan provision lay with the benefit to the carer; twenty schemes responded that giving the carer **peace of mind** and the **confidence to be able to live their own lives** were the main strengths:

“It ensures that the cared for person is kept safe in a crisis situation and it takes the pressure off the carer if they know that the cared for person is being looked after”.

Carer profile 5 provides three carers’ perceptions of the peace of mind that they get from being registered for an emergency scheme, even if they never have call to use it.

Carer profile 5: Peace of mind and confidence

JW is registered with the scheme and has not used it yet but would not hesitate to use it if the need arose. He is ninety years old and is “concerned that if something happens to me, who will look after my wife?” **JW** found the information about registering with the scheme easily. The main advantage of the scheme was that it provided him with peace of mind – “when one is a carer, one’s constant worry is what happens to one’s cared for if something happens”. He also acknowledged that it helps the carer to focus on what processes should be in place to deal with an emergency. He could not think of any negatives to the scheme.

BG has been registered for a few weeks and has not had cause to use the scheme yet. He found out about the scheme when he was visited by a Carer Support Worker representing a local Carers’ Centre. He decided to register as he lives in a rural area and thought it was a “sensible thing” to have in the event of an emergency. “The scheme feels like extra security – it gives peace of mind knowing that I can call on the emergency scheme”. He did not think there were any negatives associated with the scheme. He sees the scheme as “helpful – there is a point of contact and people of experience to help out with difficult situations”.

JS has been registered for the scheme for three years although he has had no cause to use it. He was encouraged to register after he had an emergency situation when on holiday in his caravan in which his wife had to be cared for without him being present. He found out about the scheme when a carer support worker emailed him with information about the scheme. He has not seen the scheme being advertised anywhere else but he does not see there being any barriers for carers to register as there are numerous ways of obtaining information and registering, as it can be done by an online questionnaire, through a phone call or through the post, all of which **JS** saw as a major advantage. He saw the benefits of the scheme being peace of mind, knowing that if anything was to happen the scheme would organise the alternative care for his wife. The scheme also maintains contact and provides valuable information for **JS**. “It’s a fantastic service that is offered.”

“It’s peace of mind to know that in my wallet there is a red card with a carer’s emergency alert number and my registration number on it that can be contacted, and I know that my wife will be looked after in the event of an emergency.”

Ten responses mentioned the **simplicity** of the scheme; that it is easy for a carer to register with the scheme, as it is a straightforward process, and they are able to access the service in the event of an emergency with ease. Many schemes noted that they are completely **free** for the carer to use, and six schemes acknowledged the advantage of being **accessible** 24 hours a day, 7 days a week to carers. Even if the carer does not need to access the emergency provision of care, registering with schemes encourages carers to **think about contingency plans**, and **discuss** care plans with the person they care for and anyone providing additional care: “*It makes carers think about what would happen in an emergency and puts plans in place*” (see also **Case study 5** and **Carer profile 6**).

Case study 5: Planning ahead

→ **EXAMPLE 1**

“A carer who looks after her elderly mother with dementia and has young school aged children was taken ill whilst out shopping. She was unconscious and could not tell anyone that her mother needed support at home. The paramedics found her emergency card and contacted the number to say they were taking her to the hospital. Her care plan had identified that children needed to be collected from school, and previous arrangements had been put in place to contact Children Services for respite care for the children, which was arranged, and a female carer with a specific language identified to go into the home and support the mother. If the carer had not had this card and scheme and then the mother would have been left alone for a long time without any support, and the children not collected from school. This would have caused a great deal of stress for them. The services were identified at the onset and arrangements put in place so that the children were sent to somewhere where they were familiar and the mother had a care package that identified her needs and all the tasks that needed to be carried out for, in a language she would understand. The objectives of the scheme were met, in that the carer was also at ease and made a speedy recovery knowing that the right care was in place for both the children and her mother.”

Carer profile 6: Preparing for the worst

SB noted that his scheme was beneficial as not only did it give him peace of mind, but because the registration process and form were so detailed it reminded carers of everything they need to do or remember for these kinds of situations. Also, he finds it beneficial that there is a record kept of specific details relating to the cared for person, as this would not exist in many other places, and as such makes setting things in place much easier in the event of a crisis or emergency.

Five schemes recognised the benefit to carers of **setting up** emergency plans, and that these can encourage **better care provision** by having a plan written and essential information kept with relevant care providers. Another benefit of having emergency schemes in place is the ability to **identify more carers** that other services had not identified, and also to offer **more services** to help carers in their caring roles. Some respondents reported that **their schemes were cost effective to run, easily accessible by many carers, and also often aided partnerships** between Carers’ Centres, care agencies, local authorities, and other organisations involved in supporting carers.

3.13 Weaknesses and limitations of emergency schemes

Eighteen of the schemes stated that **limited resources and funding** was a severe limitation in the provision and operation of the scheme. Many schemes are precariously funded and their funding is short-term, finite, and due to run out soon, which makes sustainability a real problem.

Six schemes mentioned that as their plans rely solely on friends and family members taking over the care duty in the event of an emergency, this relies on the control centres **being able to contact them**, and indeed their **availability** when needed. There may also be issues encountered if a carer does not keep the emergency contact **up to date** with regards to the contingency plan. It was also mentioned that there may not be anyone the carer can ask to be an emergency (nominated) contact, and therefore this alone can exclude them from setting up an emergency scheme, despite a heavy need. Indeed, paradoxically, those carers who are most isolated with no other family or friends to call on may be the most likely to be excluded from some emergency schemes.

Carer profile 7 illustrates a further concern for the operation of schemes. Here a carer expresses concern that should he become incapacitated, his wife, who has dementia, would not be able to ring for help.

Carer profile 7: Who will call for help?

BN carries a card stating that he is a carer with a number to ring in an emergency. The Red Cross already provided him and his wife with a sitting service so that he can go to the pub on a Tuesday night, and they encouraged him to register for the emergency scheme that they provide. He had never heard of the service beforehand – “it takes a couple of years to know about what is available to you”, and he frequently makes other carers aware of its existence and benefits.

BN said that he would prefer to use the sitting service he already accesses in the event of an emergency, as they know his wife already, and he worries that a “total stranger would leave me feeling a little worried.”

He is not aware of exactly what would happen or who would be contacted in the event of an emergency. He also brought up concerns about what would happen to him or his wife, who has dementia, in the event that he was incapacitated in his own house, as the scheme relies on someone to be around to notify the scheme that an emergency has actually taken place.

As indicated above, in an emergency situation it may be **difficult to implement the contingency plan due to the (non-) availability of the alternative care** provision or **the difficulty if there is no one available to report the emergency in the first place** (as in **Carer profile 7**). One scheme in the National Survey only uses volunteers to provide a sitting service for the cared for person, and as such may not be able to offer the care that is required (for example, personal care): *“The care may not always be what the carer/cared for person may like... if no help is available to support the cared for at home, they have to stay in residential care for the duration”*.

Another weakness, mentioned by seven schemes, is that of the importance for the **emergency plan to be kept up to date** by the carer, and to notify of any changes in regards to the needs of the cared for person, and the contact details of their nominated person. A few schemes operate annual reviews of the plan, however if these details are not kept up to date there may be a risk of inappropriate care being provided, or the plan may not be able to be put in place in the event of an emergency. There can also be a disparity in what the carer expects from the emergency scheme, and what can be provided, as highlighted by three respondents; for example if 'at home care' was not available, the cared for person may be unhappy at having to stay in residential care: *"The plan is only as good as the information given, and it's very important to update details as and when required"*.

A few weaknesses acknowledged by some schemes relate to the **administration and running** of the emergency schemes. Three respondents also mentioned difficulties in carers **registering** to complete an emergency plan; carers may find it challenging to fill in the paperwork and as such could provide incorrect information or be averse to using the scheme. Six schemes stated that **difficulties in signing up carers** to the scheme can be a limitation as well; this was found to be due to a lack of publicity, referrals not being made, and the lack of targeting carers who could benefit from being part of the scheme.



Some conclusions

The relative 'infancy' of most emergency schemes in Britain (although as this National Survey shows, there are a few which have been operating for some years) has meant that sustained research into the impact or outcomes of such services is yet to emerge, hence the very small number of published studies on emergency schemes in Britain reported in Section 2 of this report. It can also be problematic to evaluate these initiatives. The uptake of emergency schemes only occurs in the event of an 'emergency' or crisis, meaning evaluations of effectiveness or outcomes can be a difficult task, particularly if researchers want to ask carers and their care recipients directly about their experiences and the perceived outcomes of the scheme, especially *at the time of experiencing the emergency or crisis*. More needs to be done to develop a coherent and robust methodology for evaluating emergency schemes and for investigating the outcomes of emergency planning, especially if a concern is to identify 'what works best, and why?'. The 'Adult Carer Quality of Life Questionnaire (AC-QoL) prepared by The University of Nottingham for The Trust can be an invaluable instrument for assessing the benefits and impact of emergency care and other interventions (Elwick et al, 2011).

As we have shown, schemes can be categorised as 'Level 1' or 'Level 2', depending on who would provide the alternative care in the event of an emergency. The National Survey reported here shows that the majority of schemes in Britain today operate as a 'Level 2' scheme, with the nominated person being contacted first, and then a care agency providing the care if this person was not available. However, and perhaps disturbingly, a large proportion of schemes seemed to suggest that they would *only* contact the nominated person, and there was no alternative to the care being provided if the nominated person was unable to step in. Some schemes expressed concern that carers may not have anyone that could provide care in the event of an emergency, and so they would not even be able to register or benefit from the provision of a Level 1 emergency scheme. Another carer we interviewed reported that in some cases there may not be anyone available to actually *report* the emergency if, for example the carer is incapacitated and the cared for person has dementia or other communication difficulties. The most robust scheme, that would be as *inclusive* to as many carers as possible, would thus be a Level 2 scheme – by ensuring that care would be provided either by a nominated person or by a care agency, voluntary organisation or other provider, but the systems by which the emergency is *communicated* to that provider must be robust and 'fit for purpose'.

While schemes appear to attract many carers to register, take up or 'use', however, is reported to be relatively low, with approximately four percent of registered carers reported in this National Survey actually using an emergency scheme in any one year. This is perhaps not surprising given that these schemes exist to provide support in an *emergency* or *crisis*, rather than for day-to-day caring situations. Indeed, low use of a scheme reflects the levels of emergency during a given period (and the associated needs) rather than anything to do with carer satisfaction *per se*. The very existence of a scheme, and being registered for it, may actually reduce the likelihood of some kinds of emergency taking place (for example, a breakdown in the caring relationship, or a deterioration in the carer's physical or mental health) because of the peace of mind and reassurance that *belonging* to an emergency scheme can provide the carer *and* the cared for person. The very fact that such schemes

are available, and the carer is registered, and a plan is in place, can help to sustain the carer, promote their own mental good health and resilience, and support their ability to continue to provide day-to-day care. This should not be underestimated. Emergency schemes may actually help to *prevent* crises, and thus may help to sustain the caring relationship and help avoid the need for alternative (costly) care arrangements.

Thus, emergency schemes can be considered as *preventative* as well as *reactive* interventions and are a sound investment. There is real evidence reported in this National Survey that emergency schemes provide considerable positive benefits and outcomes to carers, to the people they look after, and to society as a whole.



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Emergency schemes directory

Scotland

The Princess Royal Trust for Carers
Borders Carers' Centre
Brewery Brig
Low Buckholmside
Galashiels
TD1 1RT
☎ 01896 752431

Wales

Conwy Carers' Card
Red Cross House
North Wales Business Park
Abergele
LL22 8LJ
✉ dworrall@redcross.org.uk
☎ 01745 828349

CAT@H Telecare Scheme
Ceredigion Carers' Emergency Card Scheme
Bodlondeb Residential Home
Penparcau
Aberystwyth
SY23 1SJ
☎ 01974 261712

Emergency Response Card
Floor 5
County Hall
Croesyceiliog
Cwmbran
NP44 2XH
✉ deborahsaunders@monmouthshire.gov.uk
☎ 01633 644567

Powys Carers' Service
Coniston House
Temple Street
Llandrinod Wells
LD1 5HG
☎ 01597 823800

Wrexham Carers' Emergency
Card Service
The British Red Cross
Croesnewydd Road
Wrexham
LL13 7TD
✉ laura.clays@wales.nhs.uk
☎ 01978 725204

North

Carers' Emergency Service
Housing 21
Killingbeck Drive
Leeds
LS14 6AH

Carers' Emergency Scheme
Children with a Disability Unit
Kirklees Council
Westfields Road
Westfields
Mirfield
WF14 9PW
✉ julie.hosty@kirklees.gov.uk
☎ 01924 326438

North West

Carers' Link
Hyndburn & Ribble Valley
Link House
23 King Street
Accrington
Lancashire
BB5 1PR
☎ 01254 387444

The Carers' Carer Service
British Red Cross
Pittman Court
Pittman Way
Fulwood
Preston
PR2 9ZG
☎ 01772 707303

The Carer's Care Service
British Red Cross
Unit 4a Springfield Court
Summerfield Road
Bolton
BL3 2NT
☎ 01204 369625

Carers' Emergency Card
Manchester Carers' Centre
Beswick House
Beswick Row
Manchester
M4 4PR
✉ admin@manchestercarers.org.uk
☎ 0161 835 2995

Trafford Carers' Centre
13 Warwick Road
Old Trafford
Manchester
M16 0QX
✉ kelly.hunter@traffordcarerscenter.org.uk
☎ 0161 8482402

Oldham Carers Emergency Support
Scheme
Princess Royal Trust for Carers
Oldham Carers' Centre
The Phoenix Centre
1 Phoenix Street
Oldham
OI1 1DB
☎ 0161 7708831

The Princess Royal Trust for Carers
Salford Carers' Centre
1 St Philip's Place
Salford
M3 6FA
☎ 0161 8330217

Emergency Card Scheme
The Bungalow
Garvenplace
Sankey Street
Warrington
WA1 1GP
✉ warrington_carers@garvenplace.
freeserve.co.uk
☎ 01925 644212

Cumbria County Council
Adult Social Care
Union Hall
Scotch Street
Whitehaven
CA28 7BG
☎ 01946 506223

North East

Carers' Emergency Support Service
Unique Homecare Ltd
Innovation House
26 Longfield Road
South Church Enterprise Park
Bishop Auckland
DL14 6XB
☎ 0191 3725499

Gateway to Care
30 Market Street
Huddersfield
HD1 2HG
✉ gatewaytocare@kirklees.gov.uk
☎ 01484 223000

Carers' Emergency Scheme
Carers Northumberland
Pegswood Community Project
Morpeth
NE61 6XG
☎ 01670 518711

Adult Social Care
Quadrant West
Silverlink North
Newcastle upon Tyne
NE27 0BY
✉ julie-ann.morrison@northtyneside.
gov.uk
☎ 0191 6432228

Carers' Emergency Card and
Emergency Card+
Carers Together in Redcar and Cleveland
23 Queen Street
Redcar
TS10 1AB
✉ carerstogether@btconnect.com
☎ 01642 488977

The Carers' Resource
15 Park View Court
St Paul's Road
Shipley
BD18 3DZ
✉ selson@carersresource.org
☎ 01274 449660

York Carers' Centre
15 Priory Street
York
YO1 6ET
✉ sarah.lewis@yorkcarerscentre.co.uk
☎ 01904 715494

Central

Crossroads
6 Queen Victoria Road
Coventry
CV1 3JH
☎ 02476 258816

Herefordshire Carers' Support
Canal Road
Hereford
HR1 2EA
☎ 01432 356068

Carers' Unit
North Wing
1st Floor Wildwood
County Hall Campus
Worcester
WR5 2NP
✉ carers@worcestershire.gov.uk
☎ 01905 728824

South West

Carers in Crises Scheme
Bournemouth Borough Council
Town Hall
Bourne Avenue
Bournemouth
BH2 6DY
☎ 01202 458204

Bristol and South Gloucestershire
Emergency Card Scheme
The Princess Royal Trust for Carers Centre
Vassal Centre
Gill Avenue
Bristol
BS16 2QQ
✉ chrish@bristol-bs.org.uk
☎ 0117 9589907

Carers' Emergency Scheme
Gloucestershire CC
Shire Hall
Gloucester
GL1 2TR
☎ 01452 426422

South East

Emergency Back Up Scheme
Tamsin Peart
Brighton & Hove City Council
Kings House
Grand Avenue
Hove
BN3 2SS
✉ tamsin.peart@brighton-hove.gov.uk
☎ 01273 295253

Carers' Support Ashford
Norman House
Beaver Business Park
Ashford
Kent
TN23 7SH
✉ manager@carers-ashford.org.uk
☎ 01233 664393

Wellbeing
Greencoat House
32 St Leonards Road
Eastbourne
East Sussex
BN21 3UT
☎ 020 88270204

West Sussex Carers' Emergency
Alert Card Scheme
c/o ICIS
35 Worthing Road
East Preston
West Sussex
BN16 1BQ
☎ 01903 777603

Medway Carers' Centre
3 Canterbury Street
Gillingham
Kent
ME7 5TP
✉ medwaycarers@aol.com
☎ 01634 577340

Suffolk Family Carers
Unit 6&8
Hill View Business Park
Old Ipswich Road
Ipswich
Suffolk
IP6 0AJ
✉ bill.priestly@suffolkfamilycarers.org
☎ 01473 835442

Carers FIRST
Emma Hanson
West Kent NHS
192 High Street
Tonbridge
TN9 1BE
☎ 01723 257555

Emergency Planning for Carers
68 St George's Street
Winchester
SO23 8AH
✉ winchester@carerscentre.com
☎ 01962 842034

London

Carers of Barking and Dagenham
15 Althorne Way
Dagenham
Essex
RM10 7AY
☎ 020 85934422

Hammersmith and Fulham Carers' Centre
182a Hammersmith Road
London
W6 7DJ
☎ 0208 5638014

Islington PCT
338-346 Goswell Road
London
EC1V 7LQ
✉ wendy.sharman@islington.gov.uk
☎ 020 75278154

Carers' Service
London Borough of Havering
Scimitar House
23 Eastern Road
Romford
Essex
RM1 3NH
☎ 01708 434639

Richmond Crossroads
1 Beverley Court
Teddington
Middlesex
TW11 8ST
☎ 0208 8917693

Wandsworth Carers' Centre
46 Balham High Road
London
SW12 9AQ
✉ emma@wandsworthcarers.org.uk
☎ 020 86750811

Carers' Contingency Team
London Borough of Greenwich
Suite 9
Gunnery House
Duke of Wellington Avenue
Woolwich
SE19 6SW
☎ 0208 3018174



Questionnaire

Emergency schemes for carers

You are invited to participate in a national survey looking into emergency schemes provided for carers. The University of Nottingham (Saul Becker, Fiona Becker, Stephen Joseph and Hannah Elwick) have designed this survey on behalf of and funded by, The Princess Royal Trust for Carers.

We are looking at the provision of schemes, interventions or projects provided by carers' organisations, social care services, third sector, voluntary, or charitable organisations, local authorities or other providers that aim to provide carers and the people they look after, support through some kind of crisis or emergency schemes for carers. The aim is to provide a report which shows what provision is available across the UK, the aims of this provision and how these schemes operate in practice. The information you provide here will be used for that report, although in an anonymised form, ensuring that no individual will be identified.

If you have any queries about the research please contact Hannah Elwick on **hannah.elwick@nottingham.ac.uk** or **0115 8458128**

Ethical approval has been obtained from the Ethics Committee of the School of Sociology and Social Policy at the University of Nottingham

Please read and answer the questions below to consent to your participation.

At the end of each page, please click 'next' to see the following page. At the end of the survey click 'done' to submit your results.

*Informed Consent

	YES
I have read the information above giving details about the research and understand what the purpose of the research is	<input type="checkbox"/>
I understand how to contact someone about the project if I have any questions or want any further information	<input type="checkbox"/>
I understand that the information I give will be collected for the purpose of drawing up a research report	<input type="checkbox"/>
I understand that no schemes will be individually identified and that my anonymity is guaranteed	<input type="checkbox"/>
I understand that the information I have give might be used for further research but my anonymity and confidentiality will be guaranteed	<input type="checkbox"/>
I agree to take part in this research study	<input type="checkbox"/>

Your Details

Name: _____

Address 1: _____

Address 2: _____

City/town: _____

Postal code: _____

Country: _____

Email: _____

Daytime phone number: _____

Your organisation:

- | | |
|--|---|
| <input type="checkbox"/> Carers' Centre | <input type="checkbox"/> Local authority |
| <input type="checkbox"/> Adult Social care/social services | <input type="checkbox"/> Children social care/social services |
| <input type="checkbox"/> Health authority | <input type="checkbox"/> Voluntary/third sector/charitable organisation |
| <input type="checkbox"/> Private sector | <input type="checkbox"/> Other (please specify) |

How many Emergency schemes are you aware of running in your area currently?

0 1 2 3 4 5

Please answer the following questions about the emergency schemes you are involved in. If you wish to give information about more schemes, you are welcome to submit information about one scheme and then re-enter the survey to complete the other schemes.

Please give the name and contact address of the project running an emergency scheme that you are involved in:

Please answer the following questions about the emergency schemes for carers that you detailed on the previous page.

→ **Please describe briefly (max 200 words) how the scheme works:**

→ **Who is the scheme aimed at? For example carers looking after individuals with particular care needs.**

→ **How long has the scheme been running for?**

→ **Approximately how many people are registered for the scheme at this moment in time?**

→ **Approximately how many people have accessed the schemes in the event of an emergency in the last three months?**

→ **What are the aims and objectives of the emergency scheme?**

→ **Is there any evidence that the emergency scheme has met the aims and objectives described above?**

- **What are the advantages and strengths of the emergency scheme?**

- **In your view, what are the limitations or weaknesses of the emergency scheme?**

- **What are the main barriers or obstacles, if any, to carers seeking help from the emergency scheme?**

- **When the scheme is contacted in the event of an emergency, what processes or actions are then taken by the organisation providing the scheme in assessing or dealing with the referral?**
 Yes No

- **Is an assessment of the emergency situation done? If 'yes', who does the assessment?**

- **What kinds of situation or emergencies arise for the carer and their family that create the need for the use of the emergency scheme?**

- **If you are able to, please give an example of a carer that has used the emergency scheme, their situation and how the objectives of the scheme were met in this case. (max 200 words.)**

→ **What is your role in the scheme? (For example, manager, worker, volunteer.)**

→ **We would like to conduct some telephone interviews with carers who have used emergency schemes such as these.**

→ **If you think you would be able to help us access a carer for these telephone interviews, please tick below and we will contact you on the details you have provided.**

Yes **No**

→ **Would you like to receive a summary of the research when it is available?**

Yes **No**

→ **If so, please give the name and address of the person we should send it to below.**

→ **When you finish this survey, will you be entering it again to give details of another emergency scheme?**

Yes **No**

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Emergency Schemes for Carers in Britain: Results of a National Survey

Hannah Elwick and Saul Becker

Emergency schemes for carers involve the establishment and delivery of an agreed plan of action, and of alternative care, in the event of an emergency affecting a carer's ability to continue to provide care. Very little is known about such schemes and how they operate in Britain.

This report provides the results of a National Survey carried out by The University of Nottingham to investigate the number and characteristics of emergency schemes in Britain today.

Forty-nine schemes provided details about how they operate, how many carers use them, what counts as an emergency or crisis, the aims of the schemes, any barriers to carers accessing the support, and their strengths and weaknesses. The report is illustrated by case studies of 10 carers who were interviewed as part of the study.

The report provides a framework to inform the future development of emergency schemes and includes a useful Directory of known schemes across Britain.

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