

How carers deal with emergencies and unplanned events

Report on a survey of carers in Nottinghamshire

Report prepared by:
Stewart Berry
October 2005

How carers deal with emergencies and unplanned events

1. Introduction

In June 2004, Carers UK conducted a national postal survey of carers to find out how they dealt with emergencies and unplanned events, and the implications of this for statutory services. A report of the survey - *Back Me Up* - was produced by Carers UK earlier this year and is available on their website. In Nottinghamshire, the survey forms were sent out by the Social Services Department to carers on their database, and copies were taken of those returned before they were forwarded to Carers UK. This report is based on an analysis of the Nottinghamshire returns.

2. Who replied?

A total of 37 carers replied to the survey (no information on the numbers sent out is available). 57% of the carers were over 65 years old and 43% aged 18 to 64 years. All of the carers described their ethnicity as "white British". Most of the carers replying (65%) lived in the Broxtowe or Rushcliffe Districts.

65% of carers cared for people 65 years or older, 32% were adults under 65 and there was one child. 6 of the 37 people cared for had a learning disability, and 14 had mental health problems.

3. How emergencies affect carers' lives

Unexpected incidents can have a drastic impact on carers' lives. Many of the experiences described by the Nottinghamshire carers in the survey mirror those reported in *Back Me Up*. In the following section I have organised examples of the effects on carers from the Nottinghamshire survey under the headings used in *Back Me Up*.

3.1 Carers own health at risk

The most common type of emergency involved the admission of a carer to hospital, or a carer being ill at home, and unable to provide care. Whilst two carers reported that adequate cover had been provided by Social Services or Red Cross whilst they were in hospital and afterwards, others experiences put their own health at risk. For example:

I was sent into hospital immediately by my GP with a heart problem. I had to leave my husband with the 'phone to ring round friends to come and sit with him while he rang agency staff to see if I could get immediate emergency cover whilst in hospital. This was all very stressful for both of us. I was very worried as to who, if anyone, would be coming in to my husband. The situation just put a lot of extra pressure on us both at the wrong time. And made us aware how reliant we were on myself keeping fit and well. And I just wanted to get home as quickly as possible.

I had an appointment for a minor op. I planned for my mother for one day- everything done...shower, shopping, etc.- so I could concentrate on the op. After the appointment I felt very poorly and my recuperation took longer than 24 hours. I pushed for a couple of days but then had no choice but to deal with my mothers needs.

Had a bad case of flu' - passed out while in sole charge of disabled son, then in bed for two weeks. Worry about household tasks and son delayed recovery. Guilt weighed heavily about my mum having to cope with both children and look after me. Husband doesn't get paid if he doesn't work - financial worries caused me more stress.

Another carer described the convoluted arrangements he had to make for his wife whilst he had an operation:

I had to travel to QMC by 'bus to have a cataract operation, and be there by 9am - a journey of over an hour. I couldn't find anyone to look after my wife from 8am and the hospital would not change the time of the appointment. My son was abroad on business. I eventually paid £58 for overnight accommodation for my wife in a home, and took a taxi home from QMC, collecting her on the way.

3.2 Families disrupted

The national survey found numerous examples of carers who were unable to get the help they needed to free them up to deal with a family crisis (for example, visit ill or dying relatives). One example in the Nottinghamshire survey involved a woman who had to leave her bedfast husband to support her son, who was suffering a mental breakdown: "I left my husband in bed (because) I thought I wouldn't be too long, but was delayed and he had no light on or food as it got dark. Rang a neighbour who had a key and put the light on, but only professional carers can look after him."

3.3 Everyday life

Everyday irritants, such as a traffic jam or a cancelled train, can become a major problem for a carer. The Nottinghamshire survey had two such examples. One involved a couple who went for a day out in the car whilst their son was at a day centre. The car broke down, and they had an anxious few hours worrying who would meet him from the 'bus at 3pm. In the event, the breakdown service got them home in time, but "we have since not felt confident about travelling far from home and consequently stay local".

Another carer took the chance of a short holiday:

A year ago I went away for a few days (the first time in 4 years). My husband suffered a major incident - i.e. lack of oxygen and heart failure. Fortunately he was being cared for by my son and daughter-in-law who were able to look after him until I returned home and took over at hospital. My daughter-in-law is now working full-time so would be unable to care for him in order for me to have a break.

What is clear from the examples given above is that it is not only an actual emergency that has an impact on carers, but also the **anticipation** of an emergency - Le. "what would happen if ?" This anticipation affects the health of carers and restricts their everyday life:

3.4 Worried sick

Carers were asked whether they worried what would happen to the person they cared for should something unexpected happen to the carer:

Carers' worried about what might happen when they were unavailable for a few hours, longer term worries about falling ill and being unable to care, and worries about the condition of the person they cared for. These affected the carers in a number of ways.

A constant level of stress and anxiety was reported by several carers:

(I'm) constantly stressed and always making up plans in my head. I often don't do things "in case I'm not back" or "something goes wrong"

Many carers also reported that anxiety affected their sleep:

The WOrry about how my son will be cared for if I was not around is constantly on my mind, waking and sleeping. I wake up at times with panic attacks and find it hard to go to sleep in the evenings, so therefore I am always tired

I wake up and worry

I'm not getting enough sleep, I'm constantly tired

Some carers were themselves in poor health, and this added to their anxiety:

My health is up and down, but I really can't afford to be ill or go into hospital for anything

It affects me mentally, and being in poor health myself it seems if I go to see my GP, I'm suffering from so many things I must be a walking miracle!

3.5 Restricted lives

Carers worried about what might happen in their absence meant that they restricted the amount of time they were away from, or available for, the person they cared for:

If I am away from home I feel the worry is always at the back of my mind, so have tended not to be away for long

I no longer stay away from home for longer than 3 or 4 hours. This means I cannot go on day trips or take part in activities that take me away from my husband for any length of time

Mother had a series of tumbles, no harm done, but was unable to get up. Each time she pressed her alarm and the Senior Link 'phoned me. I was able to be there in about 15 minutes. Since then I realised that I can no longer go away for a holiday. I have only stayed the night with friends once in almost two years and even then I couldn't relax or sleep. (No. 12)

This restriction on social activities was a common theme among the carers, and it inevitably put a strain on some relationships:

(because of the condition of my mother) I am not happy to go away on holidays leaving her on her own. This situation affects the relationship between my husband and myself.

4. Planning for the unexpected

The examples provided by carers in the survey show that, in most cases, they rely on themselves, or family, friends or neighbours in an emergency. The survey asked to what extent carers tried to plan for the unexpected.

Who has helped you plan?	Number of carers	% of carers
Nobody has spoken to me about this	18	49%
Relative or friend	9	24%
Care worker	7	19%
Social worker	4	11%
Mental health worker	4	11%
Other worker	2	5%
GP	0	0%

Almost half of the carers had not discussed how they would deal with an emergency with anyone else, and a further 7(19%) had only discussed the situation with a relative or friend (2 others had talked to relatives/friends and someone else). This meant that two-thirds of the carers (68%) had received or asked for no help from care or health workers in Lannin for the unexpected. More than half (54%) of the carers said it would help if they could speak to someone about how they might cope with unexpected events.

A carer's assessment should, on the face of it, be the opportunity to draw up a plan in partnership with social services. Almost half of the carers in the study had received an assessment:

Table 3: Have you had a carer's assessment?

Have you had a carer's assessment?	Number of carers	Percentage
Yes	17	46%
No	12	32%
Not sure	7	19%
No reply	1	3%

However only 6 of the 17 carers assessed said that Lannin for emergencies and unexpected events was discussed during the assessment. For the remainder, the subject was either not discussed, or they could not recall it being discussed.

(N.B. The finding that 7 of the carers were not sure whether they had received an assessment is not unexpected; the department's Performance Review team and Loughborough University, in separate research studies that involved interviewing carers about their assessments, found that over a third of carers

for whom Social Services had a record of an assessment had no recollection of the event!)

5. What works?

Carers were asked if they had made any practical arrangements which gave them reassurance that help would be on hand in an emergency.

peace of mind?			
16	43%	15	
41%	14	38%	
11	30%	11	
30%	11	30%	
6	16%	4	11%
2	5%		

onse team

The key role of family, neighbours and friends is clear again. However, the case studies reported by carers show that these support systems can be fragile. For example, a neighbour was away from home when needed; a son living at home at the time of an emergency has since moved away to university; a daughter-in-law who helped in the past has a new baby to care for; a daughter who lived close by has now got a job 30 miles away.

Clearly, some back-up is needed. Carers referred to a number of aids that could be used in their absence. These included a "message in a bottle" in the refrigerator (giving details of medication), fall monitors/panic buttons and the use of mobile telephones to keep in touch with the person cared for (although not so good for contact with older people with failing hearing). These are valuable, but the greatest anxiety was who would take the carers place in an emergency?

In a separate part of the survey, carers were asked to write down which services they would like to see "in an ideal world". Easily the most popular service (spontaneously mentioned by 16 of the 38 carers surveyed) was a telephone number they could call to receive a rapid response in the event of an emergency. A service that appears to meet this specification has been established in Nottinghamshire - the Nottinghamshire Emergency Card scheme, which involves the provision of a response centre that can be called by the carer in an emergency and a promise that "help will be provided to the person you care for" . Table 4 shows that 41 % of the carers in the survey referred to the value of the Emergency Card scheme, although it was not clear from the survey how many had actually joined the scheme, and none of the carers said, at the time of this survey, that they had used it.

It will be important to evaluate the effectiveness of this comparatively new scheme. Some of the comments made by carers in this survey suggest some of the criteria they would use in an evaluation:

(The) emergency card scheme requires being validated by all of the appropriate services so that in the event of it being called into action it will work or plans should be appropriately changed while time permits.

Immediate care and appropriate assistance available very quickly

Have some certainty that they will be able to help.. 'phone you back within minutes to tell you what actions they were taking

Not having to constantly justify our need for help

6. Concluding remarks and recommendations

The issues raised by the experiences and views of the 37 carers in Nottinghamshire who replied to the Carers UK survey mirror those reported in Back Me Up.

Recommendation 1: Nottinghamshire Social Services to consider the Back Me Up report, including the specific recommendations made by Carers UK, which are reproduced in the appendix to this report

Previous studies have highlighted shortcomings in the Nottinghamshire carers' assessment processes (see Berry et al, 2002 and Becker et al, 2005). The present study found that planning for emergencies appeared to receive little attention as part of carers' assessments.

Recommendation 2: Nottinghamshire Social Services to ensure that planning for emergencies is a required part of the carer's assessment, and is linked to the Carers Emergency Card scheme

The existence of the Carers Emergency Card scheme in Nottinghamshire was seen as a positive by the carers surveyed. It will be important to ensure that its effectiveness is evaluated.

Recommendation 3: The Nottinghamshire Carers Emergency Card scheme should be evaluated at an appropriate stage of its development to check on its accessibility by carers and the effectiveness of its response.

References

Serry, S., Johal, J. and Oxley, D (2002) *Carers' Experiences of being Assessed by Social Services*, Nottingham: Nottinghamshire Social Services Department

Seeker, S., Seeker, F., Silburn, R., Silburn, P., Sempik, J. (2005) *Carers' Assessments in Nottinghamshire*, Nottingham: Nottinghamshire Social Services Department

CarersUK, (2005), *Back Me Up: Supporting Carers When They Need It Most*, London: CarersUK

Appendix

BackMeUp recommendations

1. Investing in the right solutions

CARERSEMERGENCYSCHEMES

- . Every carer to be offered access to a scheme
- . Ensure 999 emergency services are part of the planning of Carers Emergency Schemes.
- . Department of Health to commission a review of best practice of Carers Emergency Schemes.
- . Fund a scheme in each local authority area.

SERVICES

- . Better investment in social and health care to enable carers to get replacement care in an emergency.
- . Make use of new flexibilities whereby services can be delivered directly to carers and/or delivered as a direct payment.

2. Giving carers the back up they need to live normal lives

PROFESSIONAL HELP

- . Ensure professional help is available to carers to help them make plans for dealing with an emergency.
- . Provide staff with training to think 'outside the box' to achieve the best outcome for each carer, rather than a 'tick box' approach. This help may be provided by a social worker, for instance as part of an assessment.
- . Encourage the involvement of the voluntary sector, such as Carers Projects, in delivering emergency planning services to carers.
- . Agencies adopt a culture which views carers as partners in providing care.

3. Ensuring carers are better informed of their rights

INFORMATION

- . Provide comprehensive information on the range of help that is available locally and ensure that it is marketed effectively.
- . Ensure frontline staff in appropriate agencies (local authority, health and voluntary organisations) are able to communicate effectively about what help is available.
- . Emergency social services contact numbers promoted effectively to carers and the general public.

TECHNOLOGY

- . Invest in new technology which enables carers and the people they care for to have greater independence.
- . Ensure that staff supporting carers are aware of current technologies that can prevent emergencies from becoming crises.

CASE MANAGEMENT

- . Have a system in place so that carers are regularly asked whether their circumstances have changed. Carers who have been assessed by social services should be offered an annual review as a minimum.
- . When cases are closed, it should still be possible for information to be easily retrieved if the carer or cared for person has an emergency.

CARERS' RIGHTS

- . Ensure carers are informed of their right to an assessment and that these are carried out in line with government guidance by addressing contingency planning.