

1. Introduction

What is Back Me Up?

Back Me Up is a campaign to improve support for carers in an emergency. There are 6 million carers in the UK, who look after a disabled relative or friend. Carers UK surveyed over 1000 carers to find out what happens if they experience an emergency or other unplanned event.

What are the concerns carers have about emergencies?

Carers know that the person they care for relies on them for vital help and support. If carers are ever faced with an emergency they need to know that replacement care will get sorted out speedily and efficiently.

What did Back Me Up find was happening to carers in an emergency?

Back Me Up found that carers are not always getting back up in an emergency. Carers lack help from professionals to help them plan for emergencies. Carers do not know who to contact. Emergency social services take too long to respond. Replacement services are simply not available. This can have devastating consequences for carers' lives.

What can be done to improve the situation?

Back Me Up found that with the right back up carers can be given the support they need to deal with emergencies and minimise the impact on their lives. This practice briefing is intended to give some background information on how professionals working with carers can improve support to carers facing a crisis.

▶ Action point ▶ visit www.carersuk.org/backmeup to read the Back Me Up report

2. Providing help at short notice or in a crisis

Policy background

The 1999 National Strategy for Carers acknowledged that many carers worry about what would happen if they had an emergency. It recommended that local carer strategies should include ways to help carers with contingency planning through schemes like Carer Emergency Cards.

▶ Action point ▶ Does your local Carers Strategy make provision for supporting carers in an emergency?

Emergency Duty Teams

Local authority social services departments provide emergency or out of hours services that can respond quickly to crisis situations. This service is usually provided through Emergency Duty Teams.

In 1998 the government's Modernising Social Services White Paper said "councils need to.. provide reliable and sufficient emergency and out of hours services... for urgent family situations where there are risks to children and where medical or other emergencies... may lead to a need for immediate social services help." They went on to say that "it is important that service users are informed of out of hours and emergency services so that they know how to get help quickly in a crisis."¹

Back Me Up found that some carers did not know how to access out of hours help from social services. A SSI investigation into Emergency Duty Teams² found that some local authorities decided against publicity for fear of raising expectations and not being able to cope with the demand.

▶ Action point ▶ Does your Local Authority advertise Emergency Duty numbers and ensure they are easy to find in local phone books?

▶ Action point ▶ Is the service made known to service users and carers at the point of assessment?

¹ (1998) *Modernising social services promoting independence, improving protection, raising standards*. Department of Health. London

² Mike Rourke (1999) "Open all hours?" – *An inspection of local authority social services emergency out of hours arrangements*. Department of Health. London

Joint working

The Carers (Equal Opportunities) Act 2004 makes provision for more joint working between social services and other bodies such as health and housing and will hopefully lead to more joint information strategies. Carers UK would like to see promotion of contingency planning included in all new information strategies for carers.

▶▶ **Action point ▶▶ Is your local authority and Primary Care Trust working together to ensure carers are supported in an emergency?**

3. Contingency Planning : being prepared**Carers' assessments**

Carers have a legal right to an assessment under the Carers (Recognition and Services) Act 1995 and the Carers and Disabled Children's Act 2000. This right will be further strengthened with the forthcoming implementation of the Carers (Equal Opportunities) Act 2004. This places a duty on local authorities to inform carers of their right to an assessment. Research by Carers UK³ suggests that only a third of carers with substantial caring responsibilities have had an assessment.

The guidance accompanying the Carers and Disabled Children's Act 2000 is explicit in stating that *contingency planning should be covered in a carer's assessment*. Contingency planning in itself can be valued by carers, even when during an assessment they do not identify a need for regular services. Staff training on assessments needs to address contingency planning, as Back Me Up found that it was covered in only 40% of carers' assessments.

▶▶ **Action point ▶▶ Does staff training on carers' assessments cover contingency planning?**

▶▶ **Action point ▶▶ Do staff who carry out carers' assessments routinely include contingency planning, even with cases where there is no call for regular services?**

Mental Health

Standard 6 of the National Service Framework for Mental health states that all individuals who provide regular and substantial care for a person on the Care Programme Approach (CPA) should have their own written care plan. This should include action to meet defined contingencies.

▶▶ **Action point ▶▶ Are NSF Mental Health Local Implementation Teams ensuring that contingency planning is included in carers' plans?**

4. Carer Emergency Schemes

Having someone at the end of the phone who could sort out replacement care was the top priority for carers for improving emergency support. This service is provided by Carer Emergency Schemes.

What is a Carer Emergency Scheme?

A typical Scheme involves a carer being asked to register. Skilled workers assist the carer to draw up their emergency plans. The plans are held by the Scheme which provides a 24 hour response service. Carers carry a card with the Scheme telephone number and a unique identification number to avoid any personal details appearing on the card. If an emergency arises, the carer or someone with them calls the Scheme. Using the unique identification number an operator looks up the emergency plan and makes arrangements for replacement care. This could be as simple as contacting friends or family, or arranging professional help. Plans will have been shared so the individual requirements of the person requiring care, such as medication, will be known by the person providing the replacement care.

How many schemes are there?

Carers UK conducted a snapshot survey of local authorities and found only about 20 such schemes out of 150 local authorities in England.

Carers UK believes every carer should be able to register with a 24 hour Carer Emergency Scheme. Until this is possible simple emergency cards can be an alternative, albeit less effective at giving carers full peace of mind.

³ Carers UK (2003) *Missed Opportunities: the impact of new rights for carers*. London

How do the Schemes differ from carrying a simple Carer Emergency Card?

Some organisations provide Carer Emergency Cards. These simply allow the carer to write down emergency contacts on a card which they carry in their purse or wallet. If the carer has an accident, the emergency services will find the card and know that they will have someone relying on them. The key difference between simple emergency cards and Carer Emergency Schemes is that the latter takes on the responsibility for arranging replacement care, leaving the carer free to deal with the emergency.

Are there any disadvantages to simple Carer Emergency Cards?

Whilst providing some peace of mind, they are not backed up by a 24 hour response service and have no pre-arranged plan. Simple cards leave too much to chance – what if the emergency contact is away on holiday? Does the emergency contact know the personal requirements of the person requiring care, such as medication? Carers may also be reluctant to put personal contact details of friends and relatives on a card that could be lost or stolen.

Case study : St Helens Carers Emergency Scheme

Under the St Helens Scheme, a skilled worker guides the carer through writing 3 different plans, depending on the seriousness of the emergency. The plans are reviewed annually. The 3 different scenarios that are planned for are :

- 1) if the carer is late home
- 2) if the carers is detained overnight such as a hospital admission
- 3) a longer term plan for more serious situations.

The scheme is available for service users and carers and funded partly from the Carers Grant and partly from health partnership funding in recognition that it improves carers' health and well being, removing anxiety about what would happen in an emergency.

► **Action Point** ► **Does your local authority have a Carer Emergency Scheme? If not could one be developed?**

5. Community Alarms

What is a Community Alarm?

There are around 300 alarm schemes across the UK. Community alarms allow people to call for help anywhere in their home. Over one and half million people use these alarms. They are aimed at older people and disabled people. They are activated by a "panic button" or alarm button" within the home.

These are run mainly by housing departments but also by social services departments. Charges vary but are around two or three pounds a week to cover renting the alarm and for the actual response service.

How do they differ to Carer Emergency Schemes?

In terms of infrastructure they are similar. They are linked to a call centre and a pre-arranged plan. However, the difference with Carer Emergency Schemes is that they can be accessed by the carer as well as the person being cared for. They can be accessed from any location by telephone and not just from a home-based panic button.

Could the two be linked?

Yes. In some areas Carer Emergency Schemes have been set up by modifying existing Community Alarm schemes and widening the eligibility. This may require a joint approach between Social Services and Housing Departments. The Carers (Equal Opportunities) Act 2004 will promote joint working between departments.

Where can I find out more?

Community Alarm schemes are registered with the Association of Social Alarm Providers (ASAP). www.asap-uk.org where you can search for a scheme local to you.

Booklet : "Calling for help: A guide to community alarms" (Ricability 020 7427 2460 www.ricability.org.uk)

► **Action Point** ► **How does your local Community Alarm scheme work? Could it be modified to include a Carer Emergency Scheme?**

6. Technical solutions

Technology is changing fast, offering help to older and disabled people. Much of this technology can have a knock on benefit for carers. Mobile phones were singled out by carers in *Back Me Up* in giving extra peace of mind. Fall detectors, automatic cooker switches, gas alarms and health monitors also help to give the carer peace of mind, with the carer knowing that should they be away, an alarm will be triggered if the older or disabled person is in trouble.

Most of this support will be provided to the older person or disabled person, but it may be that providing support directly to the carer could be the best solution, for example, providing carers with pre-paid mobile phones. Providing services directly to carers is possible under the Carers and Disabled Children Act. These services can also be delivered as direct payments opening up further choices.

Professionals need to be encouraged to inform carers, older and disabled people about these new opportunities and how they can make a difference. Carers are likely to require the assistance of professionals to be informed about the possibilities and how they will benefit their particular situation. Professionals will therefore need to be encouraged to think outside the box.

► **Action Point** ► **Does your local authority provide equipment that enhances independence and provides carers with peace of mind?**

7. How your organisation can help Back Me Up

- Please help Carers UK win national recognition for the value of Carer Emergency Schemes by adding your message of support. Visit www.carersuk.org/backmeup
- Do you know of other services that provide back up to carers in an emergency and give carers peace of mind? Contact Carers UK : backmeup@carersuk.org

8. About Carers UK

Carers UK is the leading campaigning, policy and information organisation for carers. Our work involves:

- Campaigning for a better deal for carers. Our campaigns are rooted in the experiences of carers, ensuring we speak authoritatively about what needs to change to improve carers' lives.
- Informing carers of their rights and what help is available so that they can make choices about their lives. Carers UK is the leading provider of information to carers. Our free advice service, CarersLine, receives 50,000 enquiries each year.
- Training and advising professionals who work with carers. Our trainers and consultants are leading experts in their fields. Carers UK provides the latest information on changes to policy and practice affecting carers.
- Working across the UK. Through our membership and networks of branches and affiliates, Carers UK is in touch with over half a million carers. Carers UK has a devolved structure. Carers Scotland, Carers Wales and Carers Northern Ireland determine priorities in their respective areas and ensure carers' voices are clearly heard by the Scottish Parliament and the Assemblies of Northern Ireland and Wales.

Find out more about Carers UK – visit our website www.carersuk.org

© Carers UK 2005 This document may be reproduced e.g. photocopied and used in your work, but any text must be credited to Carers UK as the holders of the copyright.