

# "You can take him home now"

Carers' experiences of hospital discharge

**carers**  
**HEALTH**  
**MATTERS**



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*"I took my husband, who has Parkinson's Disease, to hospital because he'd had a fall, was in great pain and I was worried he had broken his back. They refused to listen to me and just said 'You can take him home now. Just give him paracetamol for the pain.' We found out later that he had actually broken his back in two places. No thought was ever given as to how we would cope at home."*

## Introduction

Carers look after family, partners or friends in need of help because they are ill, frail or have a disability. The help they provide is unpaid. When the person they care for goes into hospital, the point at which they are discharged is crucial for the carer. The amount of information shared with the carer, the degree of choice about taking on caring responsibilities, the level of planning and services all directly affect the carer's health, well-being, income, ability to care and quality of life.

One study found that, since becoming a carer, 52% of respondents had been treated for a stress related disorder and half had reported sustaining a physical injury.<sup>1</sup> In Carers National Association's research, *Caring on the Breadline*, published in June 2000, six out of ten carers said they had given up work to care.<sup>2</sup> This, combined with high disability costs and low benefits, caused lasting poverty amongst carers. Six out of ten carers believed the constant worry about making ends meet was affecting their health.

## Purpose of the study

This study revisits part of an earlier piece of research - *Ignored and Invisible* - carried out by Melanie Henwood for Carers National Association in 1998. New legislation and proposals for legislation throughout the UK will affect the way that health and social care services support carers.<sup>3</sup> It is vital that carers' health issues and their experiences inform the development of policy and practice, particularly around the implementation of the NHS plans,<sup>4</sup> frameworks for supporting older people, intermediate care plans and new legislation for carers.

The purpose of this study is to:

- \* examine whether good practice is being followed in terms of informing, supporting and valuing carers at the point of hospital discharge
- \* examine whether carers' experiences of hospital discharge have changed since 1998
- \* seek carers' views about what needs to change in

order to improve their experiences of hospital discharge

- \* inform the implementation of policy and practice under the action plans for the NHS in England, Northern Ireland, Scotland and Wales

## Carers' Health Matters

This study is part of CNA's UK-wide health campaign, Carers' Health Matters. Over the course of the year, the campaign aims to:

- \* raise awareness of the difficulties faced by carers
- \* encourage the adoption of policies and practices which improve carers' health and well-being
- \* ensure that carers' views shape debates on health and the NHS
- \* encourage carers to take action which positively affects their health
- \* ensure that carers are integrated into the modernisation and partnership agenda of the NHS

Underpinned by local and national campaigning, Carers' Health Matters will seek to ensure that Government and devolved administrations' policies on health reflect carers' needs. Further aims of the campaign will be to ensure that local policy and practice is improved and that carers are more involved in NHS consultation mechanisms.

## Policy on hospital discharge

With the exception of the Mental Health Act 1983 in England and Wales and the Mental Health (Scotland) Act 1984, legislation does not specifically refer to hospital discharge practice. Policy is instead based on a number of guidance and strategic documents issued by Government and the devolved administrations.<sup>5</sup> These documents emphasise that:

- \* carers' views should be sought about discharge arrangements
- \* carers should be consulted about and involved in planning the discharge
- \* the patient should not be discharged until the

- \* appropriate support is in place in the community
- \* carers who are about to provide substantial amounts of care should be offered an assessment of their needs
- \* there should be good multi-disciplinary assessments involving health, social care and housing
- \* the patient and carer should be given a written copy of the discharge plan
- \* discharge planning should begin at admission, rather than be an end point in itself.

## Profile of respondents

The majority of respondents were carers (90%) as opposed to former carers (10%). Sixty three percent of respondents were of working age, 36% were aged 66 or over and 1% were aged under 18. Half of the respondents were caring for partners and one in four were caring for parents or parents-in-law. The majority of respondents, nearly eight out of 10, were providing over 50 hours of care per week and 63% cared for over 100 hours a week.

## Carers' experiences

Carers were asked to write about their experiences of hospital discharge, both positive and negative. Many carers reported positive experiences and paid tribute to the hard work and dedication of NHS and social care staff who supported them. However, many also reported problems, some of which had serious and, occasionally, fatal consequences. Twenty eight per cent of those commenting reported good experiences, 72% reported poor experiences.

## Change over time

The majority of respondents (52%) said the person they cared for was discharged in 2000, while 26% experienced hospital discharge in 2001. The results also highlighted repeated experiences of admission into hospital with 8% having admissions and discharges from hospital over three years. In the last few years, there has been a steep rise in the proportion of people being cared for who had to go back into hospital within two months of being discharged. The proportions rose from 19% in 1999 to 43% in 2001. The proportions of carers who felt this was due to the discharge being too early rose from 23% in 1999 to 45% in 2001. There was a corresponding fall in the total number of carers who said that they felt that the person they cared for had been sent home at the right time (67% in 1999, to 53% in 2001).

## Choice about caring

Seventy per cent of carers said they had no choice about taking on the caring responsibility when the person they were caring for left hospital. A similar

proportion of carers to the 1998 study (71%) said that they were not told about possibilities other than caring for the person at home, such as residential care or sheltered housing.

***"No doctor or any staff asked me if I would cope with the discharge and whether any help was needed. They may have spoken to my husband who is more than capable of speaking for himself, but even he forgets to ask if I am coping. I feel strongly the carer should have input."***

## Planning for the hospital discharge

Guidance on hospital discharge states that carers should be consulted about hospital discharge plans. This study reveals a fall in the proportion of carers being involved when the hospital discharge is being planned. The number of carers who said they were consulted has fallen from 71% in 1998 to 64% in this study. Correspondingly, the proportion of carers who said that their comments, concerns or ideas were not taken into account has increased from 36% in 1998 to 45%. Only 20% of carers said they received a copy of the discharge plan compared to 28% in 1998. Only half of the carers were told about the sorts of care that would be needed after leaving hospital, which is no change since 1998. However, there has been a rise in the proportion of home visits from 21% in 1998 to 33%.

***"I had no contact with social services following the discharge of my husband from hospital. Apparently we 'fell through the net'. What little services we have we have had to fight for."***

## Timely hospital discharge

The 1998 research and other studies have indicated that early discharge from hospital can have profound consequences for the carer and can increase re-admission rates.<sup>6</sup> Twenty seven per cent of people being cared for had to go back into hospital within two months of being discharged compared to one in four in 1998. Fewer carers (47%) than in 1998 (80%) felt that this was because the person they were caring for had been discharged too early. However, this is still a sufficiently high proportion to cause concern. Out of all the respondents to this survey, one in four carers felt that the patient had not been sent home at the right time and nine out of ten of these felt it was too soon.

***"I was rung just before Christmas and was told that my mother (94) was ready for discharge that afternoon. I was also told that no-one was available to help me until well after Christmas! I am 70 years old."***

***“Arrived at hospital at 3.00pm to be told husband can go home. No transport offered, no home assessment, no advice on caring for him at home. 6.00 pm waiting in draughty doorway in dressing gown for taxi. 6.30pm he almost collapsed on the driveway.”***

### **Carers' assessments**

Carers who intend to provide a regular and substantial amount of care are entitled to an assessment of their needs. This process is vital to ensure that the service package provides adequate and appropriate support for the family. From the evidence provided, the majority of carers responding to the survey would be entitled to such an assessment. Compared to 1998, the situation has improved marginally but there is still room for improvement. Fifty per cent of carers said they had been assessed, compared to 40% in 1998. A further 8% of carers were on a waiting list to be assessed. The more hours care the carer provided, the more likely they were to have an assessment. Thirty six per cent of carers providing 20 to 35 hours care per week received a carer's assessment compared to 57% of carers providing over 100 hours of care per week. However, the results also show that 60% of carers providing between 51 and 100 hours of care per week had not been assessed and only 5% of these were on a waiting list. The respondents to this survey are already part of carers' networks, and are more likely than most to be aware of their right to an assessment. This suggests that the experience of other carers could be much worse.

***“The only assessment we had was that my wife (the disabled person) was asked by a social worker, over the phone via a nurse, “do you have anyone to look after you?” On replying, ‘yes’, she was told, ‘well, you do not need any help.’ I was not consulted at all about my needs.”***

### **Support on returning home**

Our research suggests that many carers were left to cope with unacceptable caring situations. Forty two per cent of carers said that their living arrangements had changed, i.e. that they now lived with the person being cared for, since they had been discharged from hospital. A high proportion (43%) of carers said that they were not given sufficient help when the person they cared for returned home. The comments from carers highlighted a need to ensure more co-ordination between health and social care staff up to and following the discharge from hospital.

### **Employment and hospital discharge**

In this study, 21% of carers were in paid employment with the majority, 52%, working under 30 hours per week. Despite being in paid employment, 58% of these carers provided over 50 hours of care per week and 60% provided over 35 hours care per week. The results show consistently smaller proportions of carers in employment being consulted, given a choice about whether or not to care, given copies of discharge plans, being involved in decision making or having their needs assessed. For example, only 42% of carers in employment had their needs assessed compared to 51% of carers not in paid employment. Of those working 30 to 40 hours a week, only 47% of carers were consulted about the hospital discharge plan, compared to 70% of those working only up to 10 hours. Fifty eight per cent of this group of carers working 30 to 40 hours a week were still providing over 50 hours of care per week.

### **Carers from ethnic minorities**

As well as linguistic and cultural barriers to accessing support, carers from ethnic minorities also face inaccurate assumptions by the social care and health sectors that “they look after their own”.<sup>7</sup> Although our response from carers from ethnic minorities (3%) is lower than the national average (5.5%),<sup>8</sup> it provides a useful indication of the challenges faced by black and ethnic minority carers. Overall, compared to white carers, they were less likely to be consulted (56% to 64%), more likely not to have their concerns taken into account (52% to 45%) or to be involved in the planning process (23% to 34%). Re-admission within two months was more likely (38% to 26%) although this was only slightly less likely to be blamed on early hospital discharge. Higher proportions of carers from ethnic minorities (49% compared to 38%) felt that the person they cared for was not sent home at the right time and higher proportions, six out of ten carers, were not given sufficient support in the home following the hospital discharge. Carers from ethnic minorities were less likely to have been assessed (41% compared to 50%) but were more likely to be on a waiting list to be assessed (19% to 7%).

***“The interpreter was never available to communicate information to my father. This added to his confusion and anxiety. Despite several requests for an interpreter, staff felt my father could communicate sufficiently in English.”***

### **Age**

The results indicate that the older the carer, the more likely they were to feel that their concerns and

comments had been taken on board. Those most likely to report that they had been consulted were carers aged between 76 and 85 (74%) and those least likely were carers aged 26 to 35 (50%). The younger the carer, the more likely there was to be a readmission to hospital within two months. Far higher proportions of older carers thought that the person they cared for had been sent home at the right time (81% aged over 85 compared to 59% of carers aged between 26 and 35). Higher proportions of older carers had received carer's assessments. Fewer younger carers said they were given sufficient support on returning home i.e. 50% of carers aged 36 to 45 compared to 71% of carers aged between 76 and 85.

***“Hospital team builds up a completely false picture of support - none of it happened. Every time I cracked up something, not necessarily appropriate, was found e.g. shower chair after several months, washing and dressing after a few weeks, wheelchair after six months. I was led to believe there was no rural care.”***

### **Gender difference**

While many responses to questions were similar, several differences between the genders were apparent. Forty per cent of male carers were involved in planning the discharge compared to 31% of women. Fifty five per cent of men had their needs assessed compared to 47% of women and 64% of men said they had sufficient support when the person they cared for returned home compared to 54% of women.

***“The home from hospital team seemed prepared to do very little to provide practical help, never the same person, so no continuity, also very confusing for the patient, my dad, who was traumatised already.”***

***“My experience is that hospitals are understaffed. They try their best, but they are overworked. But they know in their hearts the ‘system’ is deficient, because the elderly/infirm in the main are not regarded or valued as an economic part of society.”***

***“I know he had excellent care while he was in hospital, but no-one has spoken to me about his after-care.”***

***“I felt we were completely on our own, left to sort the situation out as best we could with someone so very ill, after a massive stroke and serious operation.”***

### **Conclusion**

While the results demonstrate improvement in some areas, the overall picture is one of little change in hospital discharge. In some areas - especially in terms of consultation and involvement - there has been a deterioration in the last three years. Policy and practice issues clearly need to be addressed together with awareness about carers' own needs for involvement and support in the procedure of discharge planning.

### **Carers' Policy Messages**

Carers were asked to recommend one piece of action that NHS bosses could take to improve carers' experiences of hospital discharge. Around three quarters of the carers took this opportunity, representing over 1,000 carers. Their comments focused heavily on ensuring that good policy is translated in practice. The following is a list of their top ten recommendations ranked in order of frequency of comments:

- 1 Listen to the carer.
- 2 Ensure the carer has information on the illness, available support services and is signposted to sources of benefits information, etc.
- 3 Ensure that there are sufficient support services in place on discharge.
- 4 Give sufficient notice of, and be flexible about, timing of the discharge.
- 5 Ensure that the patient is not discharged too soon.
- 6 Improve co-ordination between health and social care, and between departments within the NHS.
- 7 Ensure that vital equipment is available at the point of hospital discharge.
- 8 Don't assume the carer can cope, give us a choice.
- 9 Ensure that there is one point of contact.
- 10 Improve the transport arrangements from hospital.

Other recommendations included improving the information given about medication such as side effects etc, giving carers written copies of the discharge plan, following up after the discharge from hospital to check the arrangements are working, and providing more services free of charge. Many respondents also took the opportunity to comment on the level of benefits and financial support which they strongly believed should be improved for carers.

***“Listen to the carer!”***

## Policy considerations and recommendations

There are an estimated 5.7 million carers throughout the UK with 855,000 providing over 50 hours of care per week.<sup>9</sup> Their support has been valued at an estimated £34 billion per year.<sup>10</sup> Recent research has also revealed that every year one third of all carers start caring and a similar proportion stops caring.<sup>11</sup> This demonstrates, therefore, a clear economic and social imperative for policy makers and practitioners to ensure that the UK's ever-changing population of carers is recognised and supported. In addition to carers' calls for action, and to achieve this aim, CNA has the following policy recommendations:

### Government, the Northern Ireland Assembly, the Scottish Executive and the Welsh Assembly should:

- \* ensure that the NHS modernisation and partnership agendas make hospital discharge procedures a priority<sup>12</sup>
- \* consider whether legislation is needed to strengthen existing guidance
- \* urgently review statutory guidance on hospital discharge with respect to carers' needs, with attention to the needs of carers who are in paid employment
- \* urgently address the shortfall in service provision for carers following discharge from hospital
- \* review the impact of early hospital discharge on the carer as well as the patient
- \* evaluate whether strategies to reduce the number of delayed discharges from hospital are resulting in carers being left with inappropriate support
- \* ensure social care performance targets on carers' assessments evaluate the proportion of carers assessed at the point of hospital discharge and record how many receive adequate services
- \* ensure benchmarking standards for NHS Trusts promote good practice and support for carers
- \* urgently identify funding for the Carers and Disabled Children Act in England and Wales and any future similar carers' legislation in Northern Ireland and Scotland.

***"I felt my son did not receive the treatment he needed on discharge. Plans were supposed to be made for his care, but I spent endless time chasing things and eight weeks went by without any contact from the hospital."***

### Local NHS bodies should:

- \* ensure that they have a well-communicated central discharge policy that incorporates key good practice points for carers
- \* evaluate different departments' discharge policies to ensure that the key good practice points are included
- \* work with local carers' groups and organisations to evaluate routinely the performance of their discharge policies for carers
- \* ensure that hospital discharge policies and practice are 'equality proofed' and are not excluding certain groups such as carers in employment, carers from ethnic minorities, younger carers or those caring for people with mental illness
- \* ensure that policies regard hospital discharge as part of a care continuum rather than the end of one type of care and the beginning of another
- \* adopt monitoring and checking procedures to ensure that carers are being involved and assessed
- \* implement carer awareness training for key staff, including consultants
- \* ensure in-house patient information services, e.g. Patient Advocacy and Liaison Services, provide carers with relevant information about discharge procedures and signpost carers to other support such as benefits advice
- \* ensure that advocacy services take account of carers' own needs
- \* ensure that local NHS implementation plans and intermediate care plans make support and recognition for carers an integral part
- \* evaluate whether strategies to record and reduce the number of "delayed" discharges are not resulting in carers being left with inappropriate levels of support.

## Results from throughout the UK

### England

Only one in four carers were given a choice about whether or not to undertake the caring role.

40% of carers said the patient was not sent home at the right time.

Nine out of 10 of these carers felt that the person they cared for went home too early.

36% of carers said they were not consulted about the discharge plan.

Half of the carers had their needs assessed.

44% of carers said the person they cared for was not given enough support on returning home.

27% of patients had to go back into hospital within two months of being discharged.

Half of these people's carers felt it was because they left hospital too early.

76% of carers were providing over 50 hours of care per week.

### Northern Ireland

Only one in four carers were given a choice about whether or not to undertake the caring role.

17% of carers said the patient was not sent home at the right time.

All of these carers said the person they cared for went home too early.

33% of carers said they were not consulted about the discharge plan.

Six out of 10 carers had their needs assessed.

61% of carers said the person they cared for was not given enough support on returning home.

17% of patients had to go back into hospital within two months of being discharged.

All of these people's carers felt it was because they left hospital too early.

71% of carers were providing over 50 hours of care per week.

### Scotland

Only one in three carers were given a choice about whether or not to undertake the caring role.

37% of carers said the patient was not sent home at the right time.

Nine out of 10 of these carers said the person they cared for left hospital too early.

34% of carers said they were not consulted about the discharge plan.

Six out of 10 carers had their needs assessed.

40% of carers said the person they cared for was not given enough support on returning home.

35% of patients had to go back into hospital within two months of being discharged.

One in three of these people's carers felt it was because they had left hospital too early.

79% of carers were providing over 50 hours of care per week.

### Wales

Only four out of 10 carers were given a choice about whether or not to undertake the caring role.

31% of carers said the patient was not sent home at the right time.

Over eight out of 10 carers said they person they cared for had left hospital too early.

39% of carers said they were not consulted about the discharge plan.

Six out of 10 carers had their needs assessed.

39% of carers said the person they cared for was not given enough support on returning home.

20% of patients had to go back into hospital within two months of being discharged.

One in eight of these people's carers felt it was because they had left hospital too early.

87% of carers were providing over 50 hours of care per week.

## Good practice versus bad practice

### Good experiences:

*"The experience was brilliant. I attended a meeting of nurses, OTs and social services at the hospital where a care plan for my wife's return was agreed, plus home visits. She was not discharged until the complete plan was in place."*

*"My aunt had been mentally ill for some weeks and was admitted into a local psycho-geriatric unit. The staff reassured me that she was safe and well and, when I visited, the key nurse came specifically to see me. I was kept well informed throughout. Since the discharge she has seen the consultant fortnightly, has had visits from her key nurse and had psychotherapy as an outpatient. Most importantly, she and I know that should anything go wrong again, then a simple phone call to the unit would suffice to summon help."*

*"My hospital has a 'step home' scheme. Each patient is monitored by a team of a doctor, nurse and physiotherapist preparatory to discharge, the home is visited and any aids like grab rails and raising the chair height and whatever is needed is provided. For six weeks a caring team came night and morning to dress and undress my partner, and social services have now replaced them. The support was and is wonderful."*

*"I care for my son who is now 19 and we have been going to a surgeon for many years. Everything is explained to us and the OT always sees us as well to make sure I can manage when he gets home."*

### Poor experiences:

*"My father-in-law is aged and lives alone. He was discharged from hospital despite being in pain and still bleeding. I am his sole carer but I also care for my own mother. I was told that even if I refused to look after him he would still be discharged because a) they wanted the bed, b) they felt there was nothing more they could do, c) of course you must realise how short of money we are."*

*"My younger sister was admitted to hospital after having had a stroke. After a couple of days, she regained the use of her limbs and speech. It was then that nursing staff wanted to discharge from hospital. Knowing that she had not been assessed, I went armed with my copy of the hospital discharge policy and voiced my concerns to a senior nurse who arranged for me to see a social worker. The social worker was very concerned that the hospital discharge plan procedure had not been followed correctly and she arranged for my sister to stay in hospital. They subsequently found more health conditions that are now being monitored. The social worker looked after her welfare whilst she was in hospital and has since visited her at home. She also kept me informed by letter and by telephone. Now that I have had two bad experiences, I dread a member of my family going into hospital."*

*"My husband was in hospital very ill, he is paralysed on the right side. I had just come home myself 10 days before having had an operation and I was awaiting another. They told me to take him home. I told them the situation and that I needed help. The ward sister was very rude to me and told me they could not keep him forever. I asked to see the hospital social worker, who never contacted me. We were still arguing about when my husband should come home when the ambulance dropped him off. I noticed he was not conscious and I had to get the district nurse who readmitted him immediately to A&E. One week later he died. I still cannot believe this happened."*

*"Admitted by ambulance to A&E, 21 February. A few tests. Go home, take antibiotics. Next day, GP visited, called 999, readmitted. Discharged 3 March contrary to my wishes. Ambulance again to go to A&E. Longer stay and recuperation at local cottage hospital. Home 25 March. 21 May during routine check up at surgery, ambulance called to go to A&E. Discharged too soon, on 4 June. On 7 June called 999 again, back on oxygen on the way to hospital. This went on until I learned about the hospital discharge drill at my carers' forum. I refused to take her home. After the right discharge procedure, help was arranged at home, the patient improved much more quickly and a better recovery than ever before."*

## Appendix

### Methodology

The questionnaire used identical questions to those in the 1998 study, with a few additions. The survey form was distributed in the March 2001 edition of Caring magazine to carer members and through CNA's Associate network totalling 930 Branches of CNA, carers' groups and carers' organisations. In Scotland, the questionnaire was distributed through their Carers magazine and through Crossroads (Caring for Carers) Scotland. CNA Northern Ireland sent out the questionnaire to 40 additional groups. CNA Wales took opportunities at CNA Branch and carers workers meetings to distribute the form. The National Black Carers Workers Network also sent copies of the forms to its network of carers workers. Carers' groups and organisations were encouraged to distribute the questionnaire beyond the membership of CNA. Sixty three per cent of respondents were members of CNA, 37% were not.

A total of 2,215 forms were returned by the closing date of 19 March and 1,409 of these involved a hospital discharge since 1999. Many of the carers had experience of hospital discharge prior to 1999 and detailed their earlier experiences. These comments and results seemed to broadly reflect the findings of this research. Of those who had experienced hospital discharge since 1999, 80% of respondents were from England, 14% from Scotland, 5% from Wales and 1% from Northern Ireland. Three per cent of respondents were from black or ethnic minority communities. Although the survey is not statistically representative, it nevertheless presents a powerful picture of the views of carers throughout the UK.

### Footnotes & References

- 1 Henwood, M. (1998) *Ignored and Invisible, carers' experience of the NHS*, Carers National Association
- 2 Holzhausen, E and Pearlman, V (2000) *Caring on Breadline, the financial implications of caring*, Carers National Association
- 3 Carers and Disabled Children Act in England and Wales and proposals for new legislation in Northern Ireland and Scotland
- 4 For England, the relevant Plan is, *The NHS Plan: A plan for investment, A plan for reform*, July 2000; *NHS Plan for Scotland: A plan for action, A plan for change*, December 2000; *Improving Health in Wales: A Plan for the NHS and its partners*, (2001), published by The Stationery Office; *Priorities for Action 2001/2002* (2001), Department of Health, Social Services and Public Safety, NI
- 5 This includes, for example, guidance on the Carers (Recognition and Services) Act 1995, the Carers and Disabled Children Act 2000 and Department of Health and Social Services guidance on carers' assessments. Other important documents include the National Service Framework for Older People (England) and intermediate care guidance (2001/01: LAC (2001)1)
- 6 Audit Commission (1997) *The Coming of Age*, HMSO
- 7 Social Services Inspectorate (1998) *They Look After Their Own, Don't They?* HMSO
- 8 Office for National Statistics, *Ethnicity in the Census*, vols 1-4 1991 Census
- 9 Rowlands, O (1998) *Informal Carers 1995 General Household Survey*, HMSO
- 10 Nuttall, S R et al. (1993) *Financing Long Term Care in Great Britain* Institute of Actuaries, London
- 11 Hirst, M (1999) 'Informal Carers - A Moving Target?' *Cash and Care - number 23*, Social Policy Research Unit, University of York
- 12 This includes the implementation and monitoring of NHS plans, National Service Frameworks for Older People, *Priorities for Action 2001/2002* (op cit)

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Researched and written by Emily Holzhausen  
Data analysis by Dave Clark and Emily Holzhausen

Carers National Association, 20-25 Glasshouse Yard, London, EC1A 4JT  
Telephone: 020 7490 8818  
Email: info@ukcarers.org  
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Registered Charity number: 246329 g:\r\hospitalsummary.qxd\501

