

CARERS look after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid.

Consultation on Regulations for the Community Care (Delayed Discharges etc.) Bill

Carers UK's Response

March 2003

1. About Carers UK

- 1.1 Carers UK is an organisation of carers, run by carers, for carers. We represent the views and interests of the six million carers throughout the UK. Carers UK provides information and advice to carers and we respond to around 20,000 enquiries annually. Through our wider network of Associates, we are in touch with around 300,000 carers.
- 1.2 We regularly ask carers about all aspects of caring and encourage them to articulate their needs and experiences to us. Their recommendations and this research inform our policy, on which this response is also founded.

2. Parts of the Consultation

- 2.1 Carers UK is responding to the three parts of the consultation:
 - The Delayed Discharges (England) Regulations 2003
 - The Community Care (Delayed Discharges etc.) Act (Qualifying Services) (England) Regulations 2003
 - Community Care (Delayed Discharges etc.) Bill – Effect of Regulations
- 2.2 We welcome the opportunity to respond to the consultation, but recognise that as the Bill is passing through Parliament, the regulations may need to be amended and reissued for consultation once the Bill has received Royal Assent. We hope that this offers an opportunity to address points raised by organisations such as Carers UK.

3. Government policy on carers in relation to hospital discharge

- 3.1 Carers UK is acutely aware of the efforts made by Government to address omissions in the Bill and ensure that carer's rights are consolidated and protected. We have already expressed our thanks and have welcomed the Government's own amendments to the Bill in relation to carers'

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CARERS UK

assessments and free services for carers under intermediate care.

- 3.2 Carers UK hopes that the following comments will be taken on Board in the spirit of the amendments currently made.

4. Delayed Discharges (England) Regulations 2003

- 4.1 Carers UK is concerned about the implications of the language used under one subsection of the draft regulations – Regulation 9(b) “days on which liability ends”.
- 4.2 We understand and agree that it is practical for a notice to be withdrawn if social services (or the responsible authority) no longer has to provide services in order to ensure that the patient is safe for discharge. We also understand that a carer may be happy to provide the care that social services would normally be under a duty to provide, if there were no carer, to ensure that the patient was safe to discharge. It would be wrong not to withdraw the notice in these instances. The wording of this section, however, that “a relative or carer of the patient takes responsibility for the care of the patient so that he no longer requires community care services” leaves us with some considerable concern.
- 4.3 Our primary concern with the wording is a point of principle. It would effectively shift the duty of care for the patient from social services to the carer or relative. Carers and relatives are not currently under a duty of care and this would introduce a new, and extremely unwelcome, scenario for carers. We do not know how this would affect their subsequent rights to request support from social services.
- 4.4 We do not believe that it is the intention of Government to place carers under a duty of care. Carers UK would prefer to see this section worded, “if the carer offers to provide care” instead of “takes responsibility for”. This is the wording used in the Department’s Note the Effect of the Regulations states, under Clause 2 that one of the reasons for withdrawing the notice is the “relative or carer offering to provide the support needed after discharge”.
- 4.5 There are a number of reasons for our concern, including a carer being under a duty of care to a patient. When both carer and patient want to go home as soon as possible, it is not difficult to see how social services might be tempted to encourage carers to take on responsibility for the patient as a means of discharging the patients quickly and, initially, cheaply. In the longer term, of course, our research shows that this has a number of consequences in terms of higher readmissions, deterioration of the patient’s health, health problems for the carer and loss of employment in some cases.

- 4.6 It would be relatively easy for a social services department to dispense with their duty of care, without having discussed the situation fully with the patient and carer or informing them of their rights. This is all covered, of course, in the discharge workbook, but we know from our research that practice does not always follow guidance. We believe it is vital that carers do not accept responsibility for the care of the patient without social services having provided information, discussed the issues fully and informed carers of their rights and we would welcome this being strengthened in guidance.
- 4.8 As a further consequence, we do not know how this would affect carers' ability to seek help if they were unable to provide the care they said they would. Although they are entitled to ask for an assessment at any point, agreeing to "take responsibility for care" from social services might prompt some departments to view this as a type of contract. Carers could then be refused support because they had already agreed to take on this support.
- 4.9 Carers UK hopes that there could be an opportunity to rectify this in the next draft of the regulations.
- 4.11 The Department of Health is also aware of Carers UK's hope that a duty to inform carers of their rights to a carer's assessment could be introduced into the legislation to mirror the provisions in Northern Ireland and Scotland.
- 4.12 We welcome the reference in the Note on the Effect of the Regulations, under Clause 2, which states that, if a carer takes responsibility for providing the care that social services would, otherwise, have had to provide, the notice would be withdrawn and reissued. We welcome this intention to withdraw and reissue the notice as we believe that this would provide a breathing space in which carers could be informed of their rights and the potential impact of their decision discussed through a carer's assessment. We do not, however, believe that this means that this obviates the need for a change in language in Regulation 9(b).
- 4.13 Although there is a reference to reissuing the notice in these situations, there is no direction in the Regulations which would prompt this action. If this is the Government's intention, Carers UK believes it would be more transparent to include this in the Regulations.

5. Community Care (Delayed Discharges etc.) Act (Qualifying Services) (England) Regulations 2003

- 5.1 Carers UK welcomes the reference to section 2 of the Carers and Disabled Children Act 2000 in the definition of community equipment, ensuring that equipment services were free to carers as well as to older people.
- 5.2 We noted, however, a omission under the definition of 'intermediate care' where there is a lack of reference to carers' services. The Department has stated that it does not, on the whole, consider community care services to be carers' services. Some community care services could be provided under s. 2 of the Carers and Disabled Children Act where the service is a community care services which are provided to the carer, but delivered to the cared for person. However, there are a whole range of carers' services that could be provided under intermediate care that would not come under this definition in the legislation but which would be purely carers' services. This might include training on lifting and handling and short-term services designed to help the carer for the six weeks following discharge.

Example 1

Mrs M's husband is about to be discharged after a serious accident has left him disabled. At this early stage he is adjusting to his new circumstances and is unwilling to contemplate being looked after by strangers. The carer's assessment identifies that Mrs M is willing and able to provide the bulk of his care, but she is terrified that her inexperience may somehow injure her husband. She wants to do it but her anxiety causes concern. A temporary package of support is agreed, under intermediate care, which includes training on how to administer medication safely as well as counselling services that help her adjust to the massive changes in their relationship and help build her confidence. This intensive package of practical and emotional support is agreed for a four week period and delivered as a carer's service.

Example 2

An older woman is discharged back home and requires intensive care. She will not consider residential care. The daughter agrees to look after her for an intensive period, getting her out of bed before she goes to work and calling in again after work. However, to do this she needs to extend her childcare arrangements temporarily as she would normally take her child to school and pick him up again. She has no one else who can do this for her. Social services agree to pay for childcare as a carer's service for the six weeks it takes the older woman to regain some of her independence.

- 5.3 For the Government's commitment to be implemented to ensure that carers have equal access to free intermediate care services in the way that older people will, it is vital for the definition of intermediate care services to refer to carers' services. The following simple amendment

could be inserted following community care service, "or a carer's service under s. 2 of the C&DC Act".

- 5.4 Carers UK is happy to discuss these matters in detail with the Department in order to find an appropriate form of wording.

6. Additional points for guidance

- 6.1 The draft regulations have also prompted a few thoughts that would be better placed in guidance rather than as additional points in regulations. For example, if a carer offers to provide care, they should be informed that they could ask for a review at any time. Carers would warmly welcome this recommendation as their comments and experience point towards being dropped into an abyss following discharge with no follow-up or support.
- 6.2 In our research, *You Can Take Him Home Now*, carers recommended that there should be follow-up visits to ensure that the carer is coping. We would suggest that there is follow-up a couple of days after discharge, if the carer is providing substantial amounts of care, then a few weeks later, followed by a six month or annual check.
- 6.3 Carers UK understands that these provisions currently exclude mental health and learning disabilities services. However, we would welcome guidance on scenarios where someone with a learning disability has acute care, but whose discharge will also involve the input of specialist learning disability services. One example might be where a person with a learning disability has a stroke or they have a complex broken bone that necessitates in-patient care. It would be helpful to have further information on how services should respond.

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