

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.

Carers UK's Response to the Draft Guidance on the Community Care (Delayed Discharges etc.) Act 2003

**England
September 2003**

1. About Carers UK

- 1.1 Carers UK (formerly Carers National Association) 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. Principle of reimbursement

- 2.1 Since the Government announced its intention to fine local authorities for each delayed discharge, Carers UK has expressed its concern that this may exacerbate early discharge. We recognise that the threat of fining has led to some local authorities, NHS Trusts and Primary Care Trusts (PCTs) working more closely together. However, we remained concerned that it could have negative effects within the system, putting more pressure on families as people are discharged too quickly. We also remain concerned that poorer performing local authorities will simply top-slice budgets in order to pay for an anticipated level of services leaving less funding for community care and carers' services.
- 2.2 We recognise and welcome the fact that Government has introduced a safeguard in the legislation for carers by introducing a duty to reassess the carer if they have had an assessment in the last 12 months and a duty to respond to a request for an assessment.

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CARERS UK

- 2.3 We particularly welcome the provision in primary legislation which states that additional services must be provided to ensure that the patient is safe to discharge. This places a higher level of duty on the responsible authority to respond to the carer's need for support than currently exists. Carers UK feels that this is the right balance in this type of situation.

3. Quality of care

- 3.1 We understand why Government has stipulated, in the guidance, that lack of capacity in a community care service will not exempt social services from their liability to pay for a service or from needing to make alternative arrangements. Whilst this is important, Carers UK would welcome a reference in guidance reminding local authorities that arrangements must be appropriate to need. In other words, lack of capacity should not mean that patients and carers are offered inappropriate services.
- 3.2 This is particularly important since the latter part of the guidance discusses situations where the patient and/or carer refuses the services being offered. If they refuse services, because they are inappropriate, they should not then be responsible for making their own arrangements. Efforts must be made by social services and health to find the right solution.

4. Continuing care

- 4.1 Carers UK welcomes the reference in paragraph 20 that screening for NHS continuing health care should be built into the assessment process as soon as possible.
- 4.2 We continue to find, primarily through our information and advice line, the CarersLine, situations where NHS Trusts are not fulfilling their duties under NHS continuing health care. Eligibility criteria still seem to be set unnecessarily high and assessments frequently do not seem to take place; experience which bears out the findings of the recent Health Service Ombudsman's report.¹ We strongly urge the Government to take this opportunity to use the guidance to remind NHS Trusts and Strategic Health Authorities that they must set reasonable criteria for NHS continuing care.

5. Assessments and service provision

- 5.1 This section in the guidance (paragraphs 38 to 52) deals mostly with assessments and not with actual service provision. Carers UK believes that this section should also remind local authorities of their duty to provide services following assessment once need has been established

and decisions made about relative balance of need within the community.

- 5.2 Carers UK's research has shown that, even if a patient and/or carer is assessed at the point of hospital discharge services promised are not always delivered. This legislation introduces a new level of duty on local authorities to ensure that services are provided, which we warmly welcome.
- 5.3 However, local authorities probably still need reminding in guidance that if services are not provided, the patient will not have been safely discharged, they would be considered at risk in the community and the local authority in breach of several duties to provide adequate care and respond to risk. We feel that this is particularly important given that the whole system will focus on assessment, and that assessment, and not the delivery of services, will trigger the fine. We are concerned that an over-focus on assessment will develop, at the expense of the delivery of services.
- 5.4 Carers UK would welcome robust monitoring procedures being set up to ensure that this does not happen.

6. Carer's assessments

- 6.1 Carers UK welcomes paragraphs 41 to 43 on carer's assessments. We believe that local authorities should also be reminded of their duty to reassess a carer if they have had an assessment in the last 12 months, as under Section 4, subsection (4)(b), and we would welcome a reference to this effect.
- 6.2 Carers UK welcomes the reference, in guidance, to offering an assessment. Even though this is consistent with guidance relating to previous Acts, we believe that reiterating this good practice is useful since actual practice and experience of carers does not always bear this out.
- 6.3 Carers UK urges the Department to consider whether a similar provision to that in Scotland and Northern Ireland could be introduced via legislation, by which local authorities and NHS Trusts are under a duty to inform carers of their rights. We feel that this would be warmly welcomed by carers, since the lack of information is one of their key concerns.
- 6.4 Carers UK has already welcomed the publication of the good practice guide to hospital discharge, *Discharge from Hospital: pathway, process and practice*. We believe the guidance would benefit from cross references in section to the good practice sections on carers in the workbook.

- 6.5 We agree that the carer need not necessarily have a full assessment, just as the disabled person may not need a full assessment, but we would find it helpful if the guidance stressed that the assessment needs to be sufficient to ensure that the patient is safe to discharge. Carers' experiences suggest that, if care plans are not followed up, further assessments may not be followed up in a similar fashion. We are also concerned that partial assessments, which are carried out too quickly, will not highlight important issues that may affect the carers' health and well-being.
- 6.6 We warmly welcome the reference in paragraph 43 to the need to inform patients and carers of the proposed date of discharge at the same time or even before social services. Although current good practice states that carers and patients must be told at least 24 hours beforehand, carers' experiences show that in many cases only a few hours notice are given and, in the worst cases, none at all.
- 6.7 We warmly welcome the reference in paragraph 43 to the need for a check to be made on any home care package within two weeks of discharge. Our research, *You Can Take Him Home Now*, highlighted huge problems around care plans, which were not delivered, or where major problems arose. Carers' primary recommendation was that someone followed up to ensure that all was functioning as expected and that the carer was coping. Carers UK would also like to suggest to the Department that it carries out a monitoring exercise to see whether this part of good practice is delivered.
- 6.8 We would also like to suggest adding another example where someone is discharged with high care needs and has a complex package of care and where the carer is new to caring. This is a time of huge stress and worry for the carer, when they feel most vulnerable and when problems are most likely to arise. A check within the first few days and then a few weeks later would be warmly welcomed by carers. It would also be an effective way to reduce the carer's stress, helping to improve their health, iron out problems before they become crises, and potentially reduce emergency re-admissions.

7. Information sharing and confidentiality

- 7.1 Carers UK welcomes the reference in paragraph 47 to the need to ensure that information is exchanged between agencies, avoiding the need for patients and carers to repeatedly give the same information. In research with carers, the lack of information sharing not only frustrates carers in having to give the same information time and again, it has also clearly led to errors and mistakes, which have had serious health consequences for

both patient and carer.

8. Patient and carer involvement

- 8.1 Carers UK warmly welcomes the reference in paragraph 90 which states that the NHS should not assume that the carer is willing and able to provide care, even if the patient says that they will. Our research has found that the vast majority of carers are not given a choice about whether or not to care and this is vital. We have come across several examples where patients have assumed carers will provide care when they are not able to.
- 8.2 In consulting patients and carers about whether they wish to be referred to social services, the NHS personnel doing the consulting must be sensitive to the fact that there is a great deal of stigma attached to social services. Most people still associate social services with child protection, working with “difficult” families, homeless people, etc. Many do not expect social services to provide home care services. It is vital that this stigma, if and where it exists, is dispelled so that carers and patients do not refuse a referral unnecessarily.
- 8.3 Rather than view Clause 2, subsection (4), as simply consultation over whether or not to refer to social services, this legislation would have far stronger effect if it were used more constructively. For example, the NHS could consult the patient and/or carer over the NHS’s analysis of the fact that the patient’s needs call for community care services and explain what social services could provide, what carers’ rights are, etc. The drafting of the legislation does not state about what the patient and carer should be consulted, providing the Department with more scope to deliver a more positive objective than simply consulting over a referral.
- 8.4 The guidance importantly directs that the NHS body and social services to ensure that the carer is fully informed and consulted if the patient refuses the referral to and help from social services. This is to prevent situations where the carer then has no choice but to provide care, because all other options have been refused by the patient.
- 8.5 This section may also benefit from the inclusion of a paragraph on risk. Local authorities are still under a duty to ensure that disabled and older people are not at severe risk in the community and have to balance risk with the needs and wishes of the patient and carer.

9. Direction on choice

- 9.1 If the patient unreasonably refuses a care package, it is vital that they are

not discharged into the carer's care without consultation with the carer. Carers UK would welcome an insertion of a similar statement into this section.

10. Resolving disagreements

10.1 It is vital that support is not denied whilst there is a disagreement between health and social services over the issuing of a notice. Too often carers report being left without services whilst health and social care argue over who is responsible for providing and/or paying for the care. It is vital that disagreements do not affect the delivery of an adequate care package in the first instance.

11. Missing sections

11.1 In reading the guidance and considering the implications for carers, we noted that there is no definition of "safe" within the legislation and guidance. What is considered "safe" has already prompted a debate within our organisation and it is likely that local authorities, NHS and Primary Care Trusts, local voluntary organisations, etc. will be having similar debates over the definition of "safe to discharge". A section in guidance on this would be welcome.

References

1. Health Service Ombudsman, *NHS Funding for Long Term Care of Older People and Disabled People*, Second Report, Session 2002-3, HC 399 (2002-2003), The Stationery Office, 2003
2. *You Can Take Him Home Now*, Carers National Association (now Carers UK), 1998