Princess Royal Trust for Carers ‘Out of Hospital’ Project – Report from Stage 1

June 2007
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Executive Summary

Successive government policies have highlighted the need to inform and involve carers fully in the hospital discharge process, but research reports published over the last ten years suggest that many carers feel insufficiently involved and unsupported in the process of hospital discharge. Furthermore, while hospital discharge policies often refer to the need to involve carers, evidence suggests that in many hospitals, with high occupancy rates and the pressure to release beds, staff cannot be relied upon to identify and support carers. In some areas, schemes have been established specifically to support carers through the transition of the cared-for person from hospital to home, but few of these initiatives have been evaluated or written up in a way that can help other hospital trusts and carers organisations improve support for carers in their own area.

Recognising this, The Princess Royal Trust for Carers decided to focus its next phase of work in the health sphere (funded by a grant from GlaxoSmithKline) on support for carers in the process of hospital discharge. They decided to commission a research project which would examine what effect support for carers at the time of hospital discharge has on:

- avoiding delayed discharges
- reducing readmission rates for those being cared for
- improving the rehabilitation/recovery of the cared-for person
- improving the carer's experience of the process of discharge
- enabling the carer to continue caring.

The research has two stages:

Stage One: A scoping review of the UK literature relating to carers and hospital discharge and a mapping exercise designed to examine the work currently being done by the Carers’ Centres across England to support carers at the time of hospital discharge.

Stage Two: Support a number of ‘Trailblazer’ projects which will build on or test out ideas identified in Stage One over an 18-month period, and which will be formally evaluated.

This report describes the findings from Stage One of the study.

Literature Review

Initially, 180 documents were identified but after applying geographical, language and date restrictions, 106 documents remained. Of these 106, there were 21 that we were not able to obtain. The remaining 85 documents were read and 53 were considered relevant to the present study. These comprised - 19 primary research documents (describing 18 studies), 10 reports, 10 policy/guidance documents, 7 discussion papers, 4 papers describing service provision/interventions and 3 review documents (including 2 systematic reviews).

Overall, there appears to be a dearth of primary research which evaluates specific interventions to improve the process of hospital discharge for carers. Of the 18 primary research studies considered relevant to the present report, only five actually involved an intervention and none of these were aimed directly at the discharge process as it related to carers. The majority of the remaining research documents examined patients’ and/or carers’ views on the process of discharge and were mainly qualitative in nature.
Of the 10 policy documents identified the majority were government publications, and all emphasise the importance of involving carers in the discharge process. In particular *Discharge from Hospital: Pathway, Process and Practice*, published by the Department of Health (2003), highlighted the role of patients and their carers as partners in care and stated as one of its ‘Key Principles’ that “the engagement and active participation of individuals and their carers as equal partners is central to the delivery of care and in the planning of a successful discharge”. The Department of Health’s guidance on discharge *Achieving timely ‘simple’ discharge from hospital – a toolkit for the multi-disciplinary team* (2004a) states that patients and their carers should be positioned firmly at the centre of care.

In terms of the provision of services, many of the documents reviewed either described services available to support carers through the process of hospital discharge of the cared-for person or discussed the effect on the carer of certain services pertaining to hospital discharge. A number of documents also discussed the issues involved in providing services to support carers at this time. The types of services described included: provision of discharge/information packs for patients and their carers, specialist carers’ workers, ward-based discharge co-ordinators, training for staff and/or carers, schemes to support carers at home immediately following discharge, hospital discharge agreements/policies, ‘hospital-at-home/early discharge schemes and pre-discharge home visits.

The evidence relating to the effectiveness of services was examined under five main themes:

- Avoiding delayed discharges
- Reducing readmission rates
- Improving the rehabilitation/recovery of the cared for person
- Improving the carer’s experience of the process of discharge
- Enabling the carer to continue caring.

The areas for consideration emerging from this literature can be summarised as follows:

- the need for communication with and involvement of carers at all stages of the discharge process
- the importance of acknowledging carers’ needs and their right to an assessment
- the recognition that the carer’s views and wishes are not always the same as those of the cared-for person and the need to consider how to balance the two
- the potential value of the carers’ specialist/key worker role
- the importance of ensuring that carers are fully aware of the options available to them
- the benefits of ongoing support and follow-up for the carer, both pre- and post-discharge
- consideration of the timing of discharge and whether the carer is fully involved in the decision-making process concerning when the cared-for person leaves hospital
- a recognition that poor discharge planning can lead to stress and anxiety in the patient and carer, a possible reduction in the carer’s ability to care and potential unplanned re-admissions.
• the advantages to both the patient and the carer of the involvement of, and participation in, the multi-disciplinary team
• the potential value of training for carers
• the necessity of encouraging communication across health and social care
• the need for increased awareness of the carer role amongst hospital staff.

Mapping Exercise

Fifty-one of the 87 Carers' Centres in England returned a completed questionnaire, giving a response rate of almost 60%. Nineteen of the centres responding reported that they provided a service designed to support carers when the person they cared for was being discharged from hospital. A further 22 centres noted that they had plans to develop targeted services but these plans were at very varied stages of development/progress. Many of the other centres noted that although they did not have dedicated services, their core services did provide support to carers around hospital discharge.

Centres were asked to provide a brief description of any services/projects they run or contribute to which are designed to support carers when the person they care for is being discharged from hospital. Five main ‘aims’ emerged, with services often having several aims:

• Identification and signposting of carers
• Direct support and advice to the carer
• Training for carers
• Provision of information
• Raising awareness and changing systems.

Most services were available to any carer of any patient using acute care in the centre’s area. The majority were being run by the carers’ centres themselves (15). Two were run by the carers’ centre jointly with the hospital Trust, one was run by the county council and the PCT, and another by the PCT. Several centres noted that the funding for the service had come from more than one source.

The centres were asked what, in their view, had been the impact of their service and their responses suggest that the main observed impact has been on improving the carer’s experience and enabling the carer to continue caring, rather than on avoiding delayed discharges and reducing admission rates which are much harder for centres to assess. Of the 19 services described, only two had been evaluated externally, six had been evaluated internally and ten reported not having carried out any form of evaluation to date (one centre noted that their service had been evaluated internally and externally).

Twenty two centres were planning to develop a new services designed to support carers when the person they care for is being discharged from hospital, but fewer than half had firm funding and start dates for the service. The main aims of the proposed services mirrored those of the existing services described above, and again, some proposed services had more than one aim. Interestingly, proportionately fewer centres (3) said that they intended to provide information in the form of packs and leaflets available in the hospital, while a greater proportion (9 centres) listed raising awareness of carers issues and/or changing systems as a key aim of their proposed service.
All the centres were asked whether they provide any wider services which help to support carers when the person they care for is being discharged from hospital. The main services provided were direct support and information, although some centres were also providing advocacy, undertaking carer training and working with hospitals and PCTs to increasing awareness of carers’ issues.

Conclusions and Recommendations

The messages which emerge from the research literature about what principles and practices might lead to effective support for carers at the time of discharge, and what policy makers expect from organisations working with carers, are relatively clear and consistent. In particular the literature suggests the need for:

- **High levels of carer awareness amongst hospital staff** – This might be achieved in many different ways (e.g. staff induction and training; designating a ‘carers’ lead’ for each ward; joint work between carers’ workers and ward staff; the creation of a carers’ charter setting out the hospital’s responsibilities to carers) but it has to be there or all other initiatives to support carers are likely to be less effective because carers will not be recognised, recorded and referred.

- **Policies and procedures which recognise carers** – Whilst carer awareness is the foundation of good support, it needs to be reinforced by policies and procedures, which emphasise the importance of involving carers in the discharge process at an early stage, acknowledge their needs and rights, and then enable staff to record carers details and wishes.

- **Easy access to information and signposting of carers** – The provision of accessible and timely information together with systems for signposting carers to sources of help and advice can clearly make the discharge process easier, especially for new carers but they are likely to be more successful if they are accompanied by high levels of carer awareness and the right policies/procedures.

- **Direct support and advice to carers** – Support and advice can be provided in many different ways, but the literature indicates that two ‘interventions’ may be particularly helpful – i) access to a specialist carers’ worker who can provide, or ensure that carers get access to, practical and emotional support both pre- and post-discharge and ii) training for carers prior to the cared-for person being discharged.

Whilst the mapping exercise showed that several centres have tried to put in place services and/or initiatives designed to make these principles and practices a reality, in many areas there is still a gap between what policy and research says should happen and what actually happens to carers as the person they care for passes through the hospital system. Even where services and initiatives to support carers through the discharge process exist, there is only limited evidence from evaluation to demonstrate their impact on the carer’s experience, and even less evidence which shows that such support can ensure discharge takes place at the appropriate time, reduce re-admission rates, and improve the rehabilitation or recovery of the person being cared for.

It is with these findings in mind that The Princess Royal Trust for Carers has decided to focus Stage Two of the Out of Hospital Project on the evaluation of initiatives which are designed to influence procedures and practice in hospital discharge. A full report from Stage Two will be available in summer 2009.
Chapter 1
Introduction and Methods

Successive government policies have highlighted the need to inform and involve carers fully in the hospital discharge process. In 2003, Discharge from Hospital: Pathway, Process and Practice, published by the Department of Health highlighted the role of patients and their carers as partners in care and stated as one of its ‘Key Principles’ that “the engagement and active participation of individuals and their carers as equal partners is central to the delivery of care and in the planning of a successful discharge”. The Department of Health’s own guidance on discharge Achieving timely ‘simple’ discharge from hospital – a toolkit for the multi-disciplinary team (2004a) states that patients and their carers should be positioned firmly at the centre of care. It goes on to note that there is a requirement placed on the multi-disciplinary team (MDT) to ensure that they gather feedback from patients and carers and keep carers informed about discharge plans from the beginning of the patient’s stay in hospital.

Despite this, successive research reports (Henwood 1998; Gasby 2003) and government reviews (Frui 1998; Comptroller and Auditor general 2003) suggests that many carers feel insufficiently involved and unsupported in the process of hospital discharge. While hospital discharge policies often refer to the need to involve carers, evidence suggests that in many hospitals, with high occupancy rates and the pressure to release beds, staff cannot be relied upon to identify and support carers (Hill and Macgregor 2001). In some areas, hospital trusts and their partner carers’ organisations have recognised this problem and have established schemes specifically designed to support carers through the transition of the cared-for person from hospital to home. A few of these schemes have been written up, but other schemes may only be known about in their local area and may never have been evaluated or written up in a way that can help other hospital trusts and carers organisations improve their support for carers around the time of hospital discharge.

Recognising this, The Princess Royal Trust For Carers decided to focus its next phase of work in the health sphere (funded by a grant from GlaxoSmithKline) on support for carers in the process of hospital discharge. They decided to commission a research project which would examine what effect support for carers at the time of hospital discharge has on:

- avoiding delayed discharges
- reducing readmission rates for those being cared for
- improving the rehabilitation/recovery of the cared-for person
- improving the carer’s experience of the process of discharge
- enabling the carer to continue caring.

The research has two stages:

Stage One: Literature Review and Mapping Exercise

There are two main parts to this first stage of the study - a scoping review of the UK literature relating to carers and hospital discharge which provides an overview of the research evidence and; a mapping exercise designed to examine the work currently being done by the Carers’ Centres across England to support carers at the time of hospital discharge.
Stage Two: ‘Trailblazer’ Projects

In Stage Two the Trust will support a number of ‘Trailblazer’ projects which will build on or test out ideas identified in Stage One. The projects will be evaluated over an 18-month to two-year period and the findings from the evaluations will be written up in a final report. Further information about the Trailblazer projects and how to get involved in them will be sent to Centres in early summer 2007.

This report describes the findings from Stage One of the study. A full report from both stages of the research will be available in summer 2009.

1.1 Methods

1.1.1 Literature Review

The literature review aimed to address two key questions:

- What is known from the existing literature about the provision of services to support carers during the process of the cared-for person being discharged from hospital?
- What is known from the existing literature about the effectiveness of services to support carers during the process of the cared-for person being discharged from hospital?

The latter question was examined particularly in relation to:

- avoiding delayed discharges
- reducing readmission rates for those being cared for
- improving the rehabilitation/recovery of the cared-for person
- improving the carer’s experience of the process of discharge
- enabling the carer to continue caring.

Various restrictions were implemented in order to focus on the most relevant documents. Only literature relating to the UK, in English and published since 1995 was included. The date restriction was imposed in order to only incorporate documents that reflected the changes in the health and social care system and the legal rights of carers brought about by the NHS and Community Care Act 1990 and the Carers (Recognition and Services) Act 1995.

Two combinations of search terms were used in the main. These were ‘carers and hospital discharge’ and ‘carers and hospital’. In addition, certain databases were searched using the term ‘older people and hospital discharge’ as we were aware that some of the relevant literature focussed on older people and their carers. Words were truncated as appropriate and the searches were conducted on the title, abstract and key words.

A range of databases and websites were searched and a variety of types of documents were found. These are listed in Appendix 1. Some limited checking of bibliographies from published studies was undertaken and additional documents were obtained where they were considered to be particularly relevant.
As this was primarily a scoping study (Arksey and O’Malley, 2005), intended to map the literature in the field and inform the second phase of the project, formal quality appraisal of the documents was not carried out.

1.1.2 Mapping Exercise
The mapping exercise gathered information about existing and planned work currently being undertaken by Carers Centres to supporting carers at the time of hospital discharge. The survey was developed in discussion with the Steering Group and two carers centre managers. A copy of the survey form is shown in Appendix 2. It was sent by post to all 87 Princess Royal Trust for Carers Centres in England and was designed to:

- find out whether the centre has any initiatives to support carers during the process of hospital discharge, or whether they are contributing to any initiatives in their area being run by other organisations (e.g. a Hospital Trust)
- gather brief information about the initiative or the centre’s work in this area (e.g. a description of the initiative, how long it has been operating, whether it has been evaluated etc.)
- collect any supporting information e.g. job description, referral protocols, evaluation reports etc.
- ask the centres to give their views on, and/or provide evidence of the impact of the initiative on, readmission rates, effectiveness of rehabilitation plans and carers’ ability to continue caring.
Chapter 2
Literature Review

This chapter explains the policy background to the study and then present the findings from the literature review in relation to the areas addressed in the research described in section 1.1.1.

2.1 Mapping the Literature

Initially, 180 documents were identified but after applying geographical, language and date restrictions as above, 106 documents remained. Of these 106, there were 21 that we were not able to obtain (or judged that to obtain them would be too difficult). These documents are listed in Appendix 3. The remaining 85 documents were read and 53 were considered relevant to the present study. The other 31 were rejected as not relevant.

The 53 relevant documents comprised:

- 19 primary research documents (describing 18 studies)
- 10 reports
- 10 policy/guidance documents
- 7 discussion papers
- 4 papers describing service provision/interventions
- 3 review documents (including 2 systematic reviews).

(See Figure 1 below)

Figure 1 Types of Document
38% of the literature covered the whole spectrum of carers, but 32% focussed on carers of older people, 13% on carers of people with stroke, 6% on carers of people suffering from cancer, 4% on carers of people undergoing surgery, 4% on carers of younger adults with complex problems, 2% on carers of people suffering from mental illness and 2% on carers of disabled children (see Figure 2 below).

**Figure 2 Categories of cared-for People covered by Documents**

It is worth highlighting that there appears to be a dearth of primary research which evaluates specific interventions to improve the process of hospital discharge for carers. Of the 18 primary research studies considered relevant to the present report, only five actually involved an intervention (Kalra et al, 2004 [and Patel et al, 2004 – the same study]; Wells et al, 2004; Gunnell et al, 2000; Dennis et al, 1997; Lundh and Williams, 1997) and none of these were aimed directly at the discharge process as it related to carers. The majority of the remaining research documents examined patients’ and/or carers’ views on the process of discharge and were mainly qualitative in nature. The three review documents mentioned above reinforce the view that there is very little empirical research being conducted which evaluates interventions designed to improve the process of hospital discharge for carers (Parker et al, 2002; Glasby 2003; Hyde et al, 2000).

### 2.2 Policy Background

As mentioned above, almost 20% (n=10) of the documents reviewed could be described as policy or guidance literature. The majority of these are government publications and are strategy, policy or good practice documents. The Community Care (Delayed Discharges etc.) Act of 2003 makes reference to carers and hospital discharge. In acknowledgment of the Carers (Recognition and Services) Act 1995, it states that where
the carer has asked for an assessment, the social services authority must assess and, after consultation with the appropriate NHS body, determine what services it will provide for a carer when the person they care for is ready for discharge from hospital.

Both the Department of Health’s (DH) *Caring about Carers: a National Strategy for Carers* (1999) and *Discharge from Hospital: Pathway, Process and Practice* (2003) highlight the need to fully inform and involve carers in the hospital discharge process. *Caring about Carers* emphasises the importance of not making assumptions about a carer’s ability or willingness to care and suggests that training of carers should be considered in the discharge process, particularly if it is the start of caring for the carer. *Discharge from Hospital* (DH, 2003) discusses the role of patients and their carers as partners in care and states as one of its ‘Key Principles’ that “the engagement and active participation of individuals and their carers as equal partners is central to the delivery of care and in the planning of a successful discharge” (p.36). Good communication between professionals and patients/carers is seen as essential and it is acknowledged that recognition of the role of the carer is necessary to ensure that all stages of the discharge process are “well managed” (p.37). It is also important to consider that the needs of the carer may differ from those of the cared-for person.

In Department of Health guidance on timely ‘simple’ discharge from hospital (DH, 2004a), patients and their carers are positioned firmly at the centre of care. There is a requirement placed on the multi-disciplinary team (MDT) to ensure that they receive “feedback from patients and carers” (p.15) and keep carers informed about discharge plans from the beginning of the patient’s stay in hospital. Interestingly, however, the example of a discharge checklist given to assist the MDT in improving the process of discharge makes no mention of carers (Factsheet 5, p.40). The *South Gloucestershire Joint Carers Strategy 2005-2010* (South Gloucester Council et al., 2005) also emphasises the necessity of carers being fully involved in the discharge planning process in order that carer recognition is improved and carers’ ability to commence or continue caring is maximised. The report advises that “access to information and advice, participation in assessment and care planning…and signposting to relevant support services should be mandatory elements of effective discharge planning which follow on from carer identification” (p.16).

Two documents which focus on services for older people stress the need for full involvement of carers in the planning and process of hospital discharge for older people (DH, 2001; Social Care Institute for Excellence [SCIE], 2005). The *National Service Framework for Older People* (DH, 2001) calls for hospital staff to be knowledgeable about discharge planning and the needs of carers. It assumes that when an older person is discharged home from hospital “the individual care plan will have identified what is needed to support the patient and their carers at home…” (p.58). In their *Research Briefing* on involving older people and their carers in the discharge process (2005), SCIE draw attention to the failure of the system to consult with carers about their own needs and concerns when the person they care for is being discharged from hospital. They also, in common with the DH (DH, 2003 – see above), stress that carers’ views may not be in line with those of the people they care for and this can lead to problems of negotiation for professionals. It is incumbent upon these professionals to consult both patients and carers about their wishes in relation to discharge from hospital:

“Carers report that they are often not consulted or kept informed about the discharge process, even though policies are frequently in place requiring the involvement of this group.” (p.10)
The Scottish Intercollegiate Guidelines Network (SIGN) has produced a set of clinical guidelines based on evidence for patients who have had a stroke (SIGN, 2002). With regard to discharge planning, a number of recommendations are made which relate to carers. As with other documents reviewed in this section, SIGN emphasises the importance of involvement of patients and their carers in discharge planning and recommends that this should be “early” and “active”. The use of family conferences should be considered, as should the provision of family support workers. SIGN recommends that the discharge process take account of the domestic circumstances of the patient. This may involve a pre-discharge home visit to identify potential and actual problems and address any other needs that the patient and/or carer may have, although there is no evidence to inform this particular practice at present (SIGN, 2002). The guidelines highlight the importance of carers being made aware of the services provided by voluntary agencies and of patients and carers being followed up post-discharge.

Guidance on discharge planning for children on long-term ventilation published by Barnardos (Noyes and Lewis, 2005) sets out some key goals for professionals to ensure a successful transition from hospital to home. Active engagement in planning by children and their carers is seen as a priority, as is a recognition of the role of parents/carers and their right for an assessment of their own needs.

The Princess Royal Trust for Carers good practice guide to identifying and supporting hidden carers (PRTC, 2003) draws attention to the feelings of disempowerment experienced by individuals and their carers when the cared-for person is admitted to hospital. The authors stress the importance of seeing discharge as “a process, not an event” and establishing this process at the earliest opportunity. They recommend that carers of people being discharged from hospital should: “feel part of the process; consider their knowledge has been used appropriately; get support in having their needs recognised and met; be able to continue caring at home if that is their wish and understand what has happened and who to contact if necessary” (p.7).

In summary, the main issues that emerge from the policy and guidance documentation are as follows:

- the necessity of recognising the role of the carer and the carer’s right to an assessment of his/her own needs
- the importance of seeing carers as equal partners in care who should be fully involved in the process of discharge from as early as possible in the hospital stay
- the value of good communication between professionals, individuals and their carers
- the importance of not making assumptions about a carer’s ability or willingness to care
- the need to consider training for carers around the time of hospital discharge of the cared-for person
- the importance of recognising that the needs and views of the carer may differ from those of the cared-for person
- consideration of the possible benefits of using a family support worker around the time of hospital discharge
- the need to ensure that carers are made aware of services available to them through the voluntary sector.
2.3 Findings – Provision of Services

Many of the documents reviewed either described services available to support carers through the process of hospital discharge of the cared-for person or discussed the effect on the carer of certain services pertaining to hospital discharge. A number of documents also discussed the issues involved in providing services to support carers at this time – these will be discussed later in this section. The types of services described included: provision of discharge/information packs for patients and their carers, specialist carers’ workers, ward-based discharge co-ordinators, training for staff and/or carers, schemes to support carers at home immediately following discharge, hospital discharge agreements/policies, ‘hospital-at-home/early discharge schemes and pre-discharge home visits. The different types of services will be considered individually below.

2.3.1 Provision of discharge/information packs

In its publication focussing on identifying and supporting hidden carers, The Princess Royal Trust for Carers describes the ‘Home from Hospital’ initiative which was developed through two carers’ centres in Scotland and aimed to support carers during and after a hospital stay (PRTC, 2003). The approach taken involved the provision of discharge packs for carers, as well as on-site availability of carers’ centre staff. The scheme identified 800 carers in the hospital setting in its first 3½ years and claimed to provide a number of benefits for carers including provision of information about services and encouragement for carers to seek out information for themselves (although no evidence is given for these benefits). Carers England, in their *Hospital Discharge Practice Briefing* (2002), report that a number of carers’ organisations surveyed in NE England had produced information packs for use both by NHS staff and patients/carers in order to assist the process of hospital discharge. The briefing emphasises the importance of regularly replacing information packs on the wards. This point is reinforced by findings from a study in Wales which sought to identify local discharge planning practices for older people and aimed to improve them where possible (Lundh and Williams, 1997). The project produced an information pack called ‘Homeward Bound’ which involved both patients and carers in their own discharge but, despite initial enthusiasm, the pack was seen to be of little use by participants in the evaluation. The authors attributed the limited success to a number of factors including stocks of the pack not being maintained on the wards, professional disagreement about the design and content of the pack, uncertainties about who the pack should be given to, contention over professional contributions to the pack (i.e. who filled in which bits) and the problem of the pack increasingly being seen as the responsibility of the nursing team and not the whole multi-disciplinary team (MDT).

2.3.2 Specialist carers’ workers

As mentioned in the previous section, the ‘Home from Hospital’ initiative employed the services of carers’ centre staff in the hospital setting (PRTC, 2003). The initiative aimed to provide carers with support at the point of discharge and allow them the opportunity to consider their own health needs. Possible benefits to hospital staff were suggested, including the support of good practice when planning discharge by encouraging recognition of carers, increased access to specialist support services to refer carers to and increased links with community services (again, no actual evidence is provided to support these benefits) (PRTC, 2003). Carers UK carried out a survey in 2002 of 1695 carers to assess the progress made concerning carers’ rights since the Carers (Recognition and Services) Act 1995 (Carers UK, 2003). The authors report on a scheme in Camden in which two carers’ workers were employed to support carers...
through hospital discharge, increase carers’ assessments and raise the profile of carers in hospitals. One part-time worker focussed on elderly care wards and the other (full-time) worker was employed to work with African and Caribbean carers on selected general wards. No evaluations of the roles were reported.

A randomised controlled trial (RCT) to evaluate the effect of contact with a stroke family care worker on stroke patients and their carers was reported in the British Medical Journal (Dennis et al., 1997). The trial took place in Scotland and involved 417 patients and 246 carers. The stroke worker decided how much contact they would have with the patient and carer but no mention was made of whether contacts were made in hospital and/or at home. The study found that carers in the intervention group were more satisfied than those in the control group with preparations for the patient’s return home, provision of information about stroke, recovery of the patient, the amount of specialist equipment provided, knowing who to contact if there were problems with caring and their ability to talk to staff in hospital about problems (Dennis et al., 1997). In another study involving the use of a family worker, a prospective audit was carried out at a Foundation Trust in London in order to explore how nurse specialists might meet the needs of family members and carers of people with lung cancer (Moore et al., 2006). The audit was carried out over a two-month period and aimed to establish the level of contact with families and carers by two lung cancer nurse specialists. 157 contacts with carers were recorded, along with a breakdown of types of support given. Almost half of the support given involved advice and information about the patient’s disease, condition, treatment and medications and a further 18% was given as ‘emotional support’. Only 4% of support was described as ‘discharge planning’ (Moore et al., 2006).

A London-based scheme for carers of older people reported in the Nursing Times (Negus, 2004) developed a new service (a carers’ specialist) as part of a unified system for intermediate care. It was observed that discharges often hinged on the involvement of carers and it was also felt that some admissions could be avoided if carers had another source of support and advice. Although the scheme was not formally evaluated, an audit found that in the first year 332 referrals were made to the service. The main interventions included family support and advice and discharge follow-up. Some initial difficulties were described, including the “unidisciplinary” approach of many general staff (who only considered the patient from the point of view of their specialism) and staff who did not normally consider the carer’s viewpoint not seeing the need for the service. Many people who might have benefited from the service were not referred and the carers’ specialist was often the one to identify those she might be able to help (Negus, 2004). A similar service was set up in North Staffordshire and was intended to improve carers’ experience of hospital discharge of elderly patients (Smith, 1999). ‘Carer Link Nurses’ were nominated from each of the wards in the community Trust and a training programme was devised in close co-operation with the North Staffordshire Carers’ Group. The main aims were to be a resource to staff, patients and carers, to disseminate information, to be a source of help and advice and to act as an advocate for carers. Posters were displayed on wards advertising the existence of the link nurse and their name. The author comments that she is “optimistic” and hopes “to reduce the number of poorly planned discharges and in the long term improve services provided to carers” (p.15).

2.3.3 Ward-based discharge co-ordinators
The research team has not found any published evaluations looking at the effects of ward-based discharge co-ordinators on carers’ experiences of hospital discharge. Two government documents, however, refer to discharge co-ordinators and the relevant information is discussed below.
The National Audit Office’s document examining what the Department of Health (DH), the NHS and other organisations have done to tackle delays in the discharge of older patients reported on the provision of discharge co-ordinators within Acute Trusts (Comptroller and Auditor General, 2003). In 1999, 70% of Acute Trusts had a discharge co-ordinator but this figure had increased to 82% in 2003. Two thirds of Trusts had also set up discharge teams as recommended by the DH’s Health and Social Care Change Agent Team. In its second annual report, the Health and Social Care Change Agent Team (CAT) set out the desired elements of a good discharge planning service and these included the provision of ward-based discharge co-ordinators who could oversee the discharge process for patients and their carers (DH, 2004b).

2.3.4 Training for staff and/or carers
A few documents discussed the value of training, either for professionals or for carers themselves and one RCT reported on by Kalra et al (2004) evaluated a training intervention for carers of stroke patients.

The Hospital Discharge Practice Briefing (Carers UK, 2002) identified three areas where training for staff could be effective: specific training on carer awareness/identification for frontline ward staff; getting carer awareness issues integrated into Trust induction programmes and delivering carer modules to students. The briefing reported that carers’ organisations often appeared to be instrumental in initiating training, but there were sometimes difficulties in implementing it, such as timing (i.e. a need for regular updating), attendance (poor if the training was not compulsory) and target audience (frontline nursing staff were important but it was also necessary to target consultants and senior medical staff). In addition to advocating training for staff, the briefing also highlights the value of training carers, particularly in nursing care tasks and lifting/handling techniques. Some carers’ centres offered support with lifting and handling and in one area, nursing staff were offering training in basic nursing tasks (Carers UK, 2002).

Kalra et al’s training programme for carers of stroke patients involved teaching carers basic nursing techniques and facilitation of personal care (2004). The setting for the study was a stroke rehabilitation unit in the south of England and the sample consisted of 300 stroke patients and their carers. All participants received conventional care but carers in the intervention group received additional training of 3-5 sessions of 30-45 minutes each while in hospital and one follow-up session at home. The trial found that the proportion of carers who were satisfied with rehabilitation and instruction in looking after the patient was higher in those who received training (Kalra et al, 2004).

In its campaign document highlighting the importance of information for stroke survivors when they leave hospital, the Stroke Association emphasised the need for educating carers in their new role and laid the burden of this training requirement at the feet of health professionals (Stroke Association, 2006). The document acknowledged, however, that “many units do not appear to have the resources to provide this facility, especially for patients managed outside stroke units” (p.3).

A study to explore carers of younger adults with complex disabilities experiences of hospital discharge recommended that in order for carers to be prepared for their caring role in the community, instruction in fulfilling this role needs to take place (Heaton et al, 1999).

2.3.5 Schemes to support carers at home immediately following discharge
The first few days or weeks immediately after the patient has returned home are often a time of “high anxiety” for the carer when help and support are required to cope with and
understand changed circumstances (Townsend et al., 2006). Davies (2000) reported that carers felt “alone and unsupported” when the person they cared for was discharged from hospital (p.322) and Holzhausen (2001) recommended that patients should not be discharged until appropriate support is in place in the community for patient and carer.

A scheme set up by the Princess Royal Trust for Carers Centre for Bristol and south Gloucestershire aimed to provide support and guidance for carers at this vulnerable time (Audit Commission, 2004). The Bristol Hospital Discharge Project “provided relevant information and special short-term support to carers during the discharge from hospital of a family member/friend” (p.25). The carer support worker made contact with the carer while the cared-for person was still in hospital and provided emotional support, advocacy, advice, sign-posting and practical help while in hospital and for up to 12 weeks post discharge. The scheme was successful in terms of allaying the fears of carers and helping them to obtain the right information and services. The Audit Commission’s report, in which the above scheme is described, aimed to look at the nature and extent of help that was available at that time for carers of older people. Carers in six different areas in England were surveyed – only 36% of them said that they had received extra support around the time of hospital discharge of the person they cared for (Audit Commission, 2004).

Wilson et al. (2002) investigated the needs of cancer patients and their carers after hospital discharge in Greater Manchester, particularly examining the role of the district nurse (DN) at this time. 71 interviews were conducted with patients and their carers both pre- and post-discharge and the authors concluded that the DN service may fill a gap in terms of support for patients and their carers in the immediate post-discharge period. Patients who were not referred to the DN service and their carers revealed a lack of support and information for carers as a major issue (Wilson et al., 2002). Carers UK (2002) suggest that ‘home from hospital’ and hospital discharge visiting schemes may be useful in providing some support for carers at this time.

2.3.6 Hospital discharge agreements/policies

The DH Change Agent Team’s guidelines on discharge planning for older people stipulated that a good service should include an agreed multi-agency discharge policy (DH, 2004b). In an earlier report for the Department of Health, Horne (1998) provided checklists for both Local Authorities (LAs) and health Trusts with regard to discharge policies. Two of these mentioned carers and charged managers to ensure that users and carers were “consulted and informed” about their care at an early stage in the assessment process and that a carer’s ability to care was also assessed if “requested and appropriate” (p.9). Authorities and Trusts were also asked whether user and carer information on hospital discharge was provided in “a range of accessible formats” (p.15). Both Carers UK and the National Audit Office (NAO) report on an area where a combined hospital discharge policy has been agreed. Northumberland County Council and Northumberland Health Authority published a joint ‘hospital discharge agreement’ in which carers were involved. Carers helped with its production and theirs and patients’ requirements were central to the agreement (Carers England, 2002; Comptroller and Auditor General, 2003).

Carers UK also highlight the need for discharge policies to “emphasise carers’ rights to assessment and choice about caring” (Carers UK, 2003, p.32). Hill and Macgregor (2001), in their study for Carers UK looking at hospital discharge policies in 23 NHS Trusts in north west England, indicated that policies should reinforce what Trusts should be doing to support carers at discharge, notably acknowledging that carers should have a choice about caring, taking steps to identify the carer, ensuring carers are informed
about sources of help, giving carers a copy of the discharge plan, giving carers key
information about the cared-for person (subject to their consent) and involving carers in
pre-discharge home assessments. The authors reported, however, that even when
discharge policies say carers should be consulted, few of the Trusts examined put this
into practice (Hill and Macgregor, 2001).

2.3.7 'Hospital at home' and early discharge schemes
The research team reviewed two RCTs which looked at the effects of early discharge on
carer burden. Gunnell et al (2000) focussed on carers of older people and measured
carer strain in 133 carers: 93 carers of patients who received a ‘hospital at home’
service and 40 carers who received usual hospital care and discharge. Wells et al
(2004) evaluated the effectiveness of a nurse-led model of early discharge for breast
cancer surgery patients and measured carer burden in 86 carers. Neither study found
evidence of an increase in self-reported burden imposed on carers of patients
discharged home early. In Gunnell et al’s trial, this was despite the fact that carers in
the intervention group looked after patients for a median of seven additional days at
home. The authors surmised that carer strain was similar in both groups because
carers in the intervention group received more information about the patient’s treatment
and care and felt more involved in decision making through their regular contact with
‘hospital at home’ staff (Gunnell et al, 2000). Wells et al reported that 90% of carers in
the intervention group would choose the same method of care again, as opposed to
78% in the control group. The control group of carers were particularly dissatisfied with
the lack of communication between themselves and health professionals and between
the hospital and the GP (Wells et al, 2004).

2.3.8 Pre-discharge home visits
In Henwood’s examination of carers’ experiences of the NHS, carers were asked about
their involvement in planning for discharge of the cared-for person. Approximately
three quarters of carers did not have a pre-discharge home visit arranged by those
planning the discharge (Henwood, 1998). In Holzhausen’s follow-up study in 2001, this
proportion had dropped to two thirds (Holzhausen, 2001). Although this could be seen
as a positive change in that it shows greater involvement on the part of carers in the
process of hospital discharge, the authors of one discussion paper question the whole
notion of pre-discharge home visits for older people and their carers (Mountain and
Pighills, 2003). They consider whether pre-discharge visits are necessary or helpful
and suggest that they can engender anxiety both in patients and their carers. They
argue that as pre-discharge home visits can be critical in determining the future living
options for people who have been in hospital and their carers, their effectiveness should
be evaluated properly. There is, however, very little literature looking at the outcomes
from the user and carer perspectives. Although carers are often invited to the pre-
discharge visit, this “overtly simple process belies the complexity of assessing and
balancing the needs of relatives and carers with the desire of the person to return home”

Various issues involved in providing services to support carers around the time of
hospital discharge were raised by many of the documents reviewed. These have been
grouped according to theme and are discussed below.

2.3.9 Involvement of carers in the discharge process
Carers England (2002) believe that involvement of carers is an essential part of good
practice in hospital discharge. They suggest that the process “offers an opportunity for
carers to be involved in decisions relating to the care of the patient, as well as their own
needs as carers. This approach values carers as partners in the provision of health and social care” (p.1). The DH Change Agent Team also advocates carer involvement and indicates that this involvement must be “active” if discharge planning is to be successful (DH, 2004b). In a study by the Commission for Social Care Inspection (CSCI) looking at the outcomes achieved by older people following hospital discharge, it is suggested that the role played by family carers at times of crisis (including hospital admission and discharge) can have a critical bearing on what happens. Actively addressing the anxieties of carers and engaging them in risk assessment and contingency planning at an early stage can assist the calm management of crises when they occur (CSCI, 2005).

Despite this emphasis on involvement of carers, much of the evidence available indicates that carers are often left out of the process of hospital discharge. In the NAO’s report on effective discharge for older people, almost 100% of Trusts surveyed said that they involved carers in discharge planning, but in their consultation with older people, the NAO found that “relatively few” carers were actively involved. Many carers thought they had little involvement and information prior to discharge and only one in five received a copy of the discharge plan (Comptroller and Auditor General, 2003). The report concludes that “this disparity in perceptions emphasises the need for trusts to improve communication with patients and carers” (p.24).

Fruin (1998) in his report for the DH on Social Services Departments’ implementation of the 1995 Carers Act, stated that “during the inspections, carers and social services staff cited cases where carers had been insufficiently involved in discharge of patients from both acute and mental health hospitals” (p.24). In their systematic review of RCTs involving discharge interventions for older people, Parker et al (2002) highlighted the anxiety felt by frail older people and their carers around the time of hospital discharge and indicated that patients and carers are often not involved in the process of discharge planning. Glasby (2003) also concluded from his review of hospital discharge processes that carers were not included enough and wished to be more actively involved. Good practice in discharging patients should require that patients and their carers are actively involved from the outset.

Henwood (1998) distinguishes between being consulted and being properly involved. 71% of the carers who were surveyed about their experiences of hospital discharge indicated that they had been consulted about discharge plans but far fewer had actually been fully involved in the process. About a third of carers thought that their comments, concerns or ideas had not been taken into account by staff and more than 40% felt that staff had not helped them prepare for imminent discharge (Henwood, 1998). In the follow-up study (Holzhausen, 2001), the proportion of carers who felt that they had been consulted had gone down from 71% to 64% and the proportion who felt that their views had not been taken into account had gone up (36% to 45%). Holzhausen recommends that carers’ views should be sought about discharge arrangements and that carers should be involved in planning discharge (Holzhausen, 2001).

Other authors also recommend that carers should be involved in the planning process. Heaton et al (1999) propose that carers need independent consultation and participation in discharge planning and Pearson et al (2004), based on the findings from a study looking at the process of hospital discharge for medical patients, emphasise the importance of active involvement of patients and carers in the discharge process. In a study that attempted to identify the components of effective discharge planning for elderly people, it was found that if the patient and carer were not involved in the planning process then the professionals were more likely to have to revise the plan (Bull and Roberts, 2001). Becker (1998), commenting on Arksey, Heaton and Sloper’s 1997 study Coming Home (which is reported on in Heaton et al [1999]), advises that:
“From the carers’ perspective, ‘effective’ hospital discharge procedures means they should be recognised and addressed as active participants in their own right throughout, with systematic monitoring to ensure this takes place.”

(p.40)

2.3.10 Consultation and communication

A number of documents stressed the importance of sustained and systematic communication between professionals, patients and their carers and some revealed concerns from carers about poor consultation and communication. Townsend et al (2006) reported that carers of older people were often worried around the time of hospital discharge and sought reassurance from knowledgeable staff. The authors suggest that communication (chats with support workers, for example) can provide an opportunity to express concerns that can be built into assessment and ongoing support. The Royal College of Physicians National Clinical Guidelines for Stroke (2004, cited in Stroke Association, 2006) recommend that hospitals should have information protocols which are designed to ensure that, before discharge, patients and their families/carers are given information about, and offered contact with, appropriate statutory and voluntary services.

Bull and Roberts (2001) cite a number of studies from America and Australia that found communication gaps between health care providers and family carers during discharge planning. Across these studies carers consistently expressed a need for information about the patient’s condition, medication etc. Bull and Roberts emphasise the need for “ongoing, open and honest communication” with the patient and their family/carer and express the view that this is “vital” for an effective discharge (p.575). Wilson et al (2002) also report an “information gap” between professionals and carers, particularly in the immediate post-discharge period. As mentioned above, the authors postulate that the district nursing service may have a part to play in filling this gap.

Becker (1998), again commenting on Arksey et al (1997), highlights that a lack of information was a key complaint among carers. Some carers were getting information but they wanted more, particularly in relation to the cared-for person’s medical condition, what they could do or not do after discharge and what services were available to them when they got home. In the NAO’s report about hospital discharge for older patients, some of the same themes emerge. Many patients and carers felt poorly informed about the range of care services available, whom to contact for additional help and the provision of services after discharge (Comptroller and Auditor General, 2003). The NAO recommend that “Trusts should examine current practices for involving patients and carers to ensure they are meeting expectations. Discussions should include providing full information on options available and supplying patients and carers with a discharge plan” (p.9).

Other studies which have found that carers would like more information include Shepherd (1996), Henwood (1998), Parker et al (2002), Edwards (2003), Glasby (2003) and Swain et al (2007). Some of the findings will be examined in more detail in later sections, but a few will be discussed here. Henwood found that almost half of the carers involved in her study had not been told about the type of care the patient would need after discharge and almost three-quarters had not received a copy of the discharge plan (Henwood, 1998). She concludes that these experiences indicate that poor communication is still prevalent and that carers are “too often left to cope with inadequate information and insufficient support” (p.39). In Parker et al’s systematic review of discharge arrangements for older people (2002), the authors conclude that
poor consultation and communication can lead to dissatisfied patients and carers, and recommend that focussing on patient and carer satisfaction with discharge, assessment and meeting care needs is central in discharge planning. Edwards (2003), in her good practice guidance for keeping stroke patients and carers informed, highlights the need for individualised and targeted information for patients and carers and suggests that specific information is more likely to impact on behavioural changes and make better use of resources. Swain et al (2007) agree that patients and carers benefit most from personalised and timely help to navigate the routes to relevant information. The authors found that the patients and carers, in their study on accessing information in health and social care, did not feel that there was a shortage of services but that they were just not made aware of what was available to them at the right time.

2.3.11 Carers’ needs and views
The need to actively seek out and act on carers’ needs and views is an issue raised by a number of the documents reviewed. In some of these, this relates to choice in care-giving and focuses on the individual carer but in others, the potential conflict between carers’ views and those of the cared-for person is highlighted.

There is some evidence that carers are not always made aware of the options they may have in terms of care-giving. Henwood (1998) found that over 70% of the carers in her study had not been told about any options other than continuing to care for the person at home, although the likelihood of options being discussed increased with the age of the cared-for person. In the follow-up study, a similar proportion was still unaware of any other caring option other than looking after the person themselves (Holzhausen, 2001). Becker (2001), in his discussion paper on the Holzhausen study, suggests that the degree of choice that the carer has about taking on caring responsibilities can directly affect the carer’s “health, well-being, income, ability to care and quality of life” (p.10). Negus (2004) highlights the problem of professionals assuming that family members/carers are able or willing to take on a caring role without assessing the need for support.

Several documents discussed the potential discrepancy between the carer’s views and those of the cared-for person. Shepherd (1996) found that over a third of the older people interviewed for their study into experiences of hospital discharge had different views to their carers about the length of hospital stay. All but one of these carers felt that the older person’s hospital stay should have been longer. Davies (2000) also found a discrepancy between how long carers felt the cared-for person should have stayed in hospital and how long the patient felt they should have stayed. The study examined the congruence between patients’ and carers’ perceptions of recovery following cardiac surgery and involved 40 patients and their carers. One week after discharge, two thirds of carers thought that the patient should have stayed longer, but two thirds of patients were satisfied with the timing of discharge. Townsend et al (2006) suggest that there is a need for additional focus on appropriate professional responses to the differing relational aspects of care-giving, for example, where user and carer views diverge. Proctor et al (2001) acknowledge that patient and carer must be at the centre of the discharge process – “however, in placing the patient and carer at the centre...there is a need for practitioners to be sensitive to the dynamics of patient/carer relationship and not assume that their needs are synonymous, or that the carer shares the same understanding of their role as others involved in the discharge process” (p.207). Their study aimed to obtain an in-depth understanding of the process of discharge experienced by patients ‘at risk’ of unplanned readmission to hospital or delayed discharge, and their carers, and involved pre- and post-discharge interviews with 11 patient/carer ‘dyads’. As a result of their findings, the authors suggest three
problems that can cause difficulties when arranging discharge. These are: the complexity of the patient/carer relationship (the patient may see the home situation differently to the carer), the assumption that the carer can cope can lead to other sources of support for the patient not being explored and the carer’s needs not being recognised. They suggest that “the sanctity of the professional/patient relationship and the concern not to override the expressed wishes of the patient creates difficulties for professionals in challenging the patient’s interpretation of the role of family members or other informal carers in meeting their care needs” (p.214).

Heaton et al (1999) concluded from their study of carers’ experience of hospital discharge that there is a tension between the patient-centred nature of the process and carers’ desire to be involved. They found that although carers’ views were rarely overlooked completely, the patients’ needs and wishes tended to take priority. The authors suggest that “the lack of clarity over the rights of carers vis-à-vis patients needs to be addressed” (p.98) and they believe that an over-emphasis on patients’ needs and an under-emphasis on carers’ needs is unlikely to benefit either patients or carers in the long term. In their report on outcomes achieved by older people discharged from hospital, CSCI (2005) also discovered a mismatch between the views of carers and those they cared for. Although patients were largely satisfied with their care and grateful for the help they received, family carers were more likely to voice grievances. As Mountain and Pighills (2003) conclude:

“This highlights a requirement for professionals to listen separately to the individual views of the older person and their carers.”

(p.150)

2.3.12 Carers’ identification and assessment
A few documents draw attention to the importance of identifying carers and raising awareness of their right to an assessment. Addressing the needs of carers assumes that the carer can be clearly identified and that they have consented to taking on the role (Proctor et al, 2001). In their Hospital Discharge Practice Briefing, Carers England found that most hospital staff were unaware of carers’ assessments, although they did find a few exceptions, for example, one mental health trust trained hospital staff in carers’ assessments (Carers England, 2002). Glasby (2003) found that carers often did not receive an assessment of their needs under the Carers Act 1995. Henwood’s study (1998) agrees with this, as only 40% of carers had received an assessment, with this figure rising to 50% in Holzhausen’s follow-up survey (2001). Holzhausen found that whether the carer received an assessment was related to the amount of caring they did; the more hours they cared for, the more likely they were to receive an assessment. Wilson et al (2002) highlight the problem of unrelated, non-resident carers, suggesting that identification of these carers is more difficult and raising the question of how to keep them informed without compromising patient confidentiality. In the DH Social Services Inspectorate report investigating local authority support for carers (Fruin, 1998), this sub-group of carers is also called attention to. The inspectors found that this was a particularly weak area in terms of identification and support.

2.3.13 Joint working
Several authors stress that in order for the discharge process to be successful from the point of view of carers as well as patients there is need for joint working, both within the hospital environment and between hospital staff and external organisations. The Department of Health recommends that a good discharge planning service should include a mix of professionals such as nurses, social workers and therapists, and that
they should be located together in the same team (DH, 2004b). Specialist carers’ workers can be a vital link in multi-disciplinary teams and can also be useful in bridging the gap between hospital and community services (Negus, 2004). Pearson et al (2004) suggest that there are four sets of players in the process of hospital discharge (hospital-based professionals, community-based professionals, patients and carers) and that they must all work together to make the discharge successful. Fruin (1998) emphasises the need for social and health services to work together to make sure carers are fully involved when the cared-for person is discharged from hospital, as does Holzhausen (2001). Holzhausen also stresses, along with Carers England (2002), the importance of statutory organisations working with voluntary carers groups in order to ensure that discharge processes are taking carers into account.

2.4 Findings – Effectiveness of Services

2.4.1 Avoiding delayed discharges

Citing a report published by the NAO in 2000 looking at admissions and bed management in hospitals, Glasby (2003) sets out the reasons offered by Acute Trusts for delayed discharges from hospital. A number are given, such as delays in take home medicines, delays in transport, lack of residential/nursing home places and delays in social services assessment, but no mention is made of lack of carer involvement contributing to delays. However, according to the small amount of evidence from research, certain interventions with carers can facilitate timely discharge.

In the NAO’s report into discharge of older patients, it was found that delays can be caused by a lack of information on options and a lack of support being given to patients and carers. The report suggests that involvement of patients and carers is “key to timely and appropriate discharge of older patients” (Comptroller and Auditor General, 2003, p.4). The Audit Commission also points to carer support as a necessary adjunct to timely discharge for older people. The Bristol Hospital Discharge Project, which employed two half-time workers to support carers of older people leaving hospital, found that supporting carers around the time of hospital discharge could reduce delayed transfers of care, although this was not quantified in terms of estimated savings (Audit Commission, 2004). The use of a family support worker for carers of stroke patients also appeared to reduce the length of hospital stay in Dennis et al’s study (1997). In this RCT, those who were allocated the stroke family care worker had, on average, a slightly shorter hospital stay than those in the control group.

The other intervention that has been evaluated and appears to have an effect on timing of discharge, at least in stroke patients, is that of carer training. As part of Kalra et al’s RCT into training carers of stroke patients (2004, described earlier in this review), an economic evaluation was done and reported on by Patel et al (2004). This evaluation found that the annual costs for those in the intervention group were significantly lower than those in the control group. This was mainly due to a shorter initial hospital stay rather than reduced costs in the 12 months after stroke. The researchers suggest that the most likely reason for the shorter hospital stay was that “training and some input into care before discharge may have increased the confidence and competence of caregivers” (Patel et al, 2004, p.1103).

Two documents point to the possible conflict between the desire not to delay discharge and the need to involve carers in the process. Taking account of carers’ needs and views and including them in assessment can take time and this may be at odds with a service priority to achieve rapid discharge from hospital (Social Services Inspectorate,
Princess Royal Trust for Carers 'Out of Hospital' Project – Report from Stage 1 June 2007

1995). Parker et al (2002) warn of the burden that may be imposed on the carer if a patient is discharged early. Even if the discharge is managed well from the point of view of the patient, the increased burden may be too much for the carer in the long term and may lead to them becoming ill or deciding that they have "had enough".

2.4.2 Reducing readmission rates

Early discharge in an attempt to avoid delays may have an impact on readmission rates. Henwood (1998) found that 20% of carers surveyed thought that the cared-for person had been discharged too soon. A quarter of the patients were readmitted to hospital within two months of discharge but it was not clear how many of these were emergency admissions. Henwood surmises that at least some of them may have been because the patient was discharged too soon. In Holzhausen’s follow-up (2001), there were slightly more re-admissions within two months (27%) and slightly more carers thought that the cared-for person had been discharged too early (22.5%). Of the patients who were re-admitted, however, nearly half (47%) of their carers thought that it was because they had been discharged too early. Holzhausen also found that patients with carers from ethnic minorities were more likely to be re-admitted to hospital (38%), as were patients who had younger carers.

Proctor et al (2001) reported that seven out of eleven patients whose carers were interviewed were re-admitted to hospital within six weeks of discharge. In some cases, it appeared that this was due to the patients’ attitude to their health and their refusal to acknowledge the impact of their illness on their lives, but in at least one case the carer’s inability to cope at home was probably the cause of re-admission.

The SSI (1995) suggest that poor discharge planning and lack of support for carers around the time of hospital discharge can lead to avoidable re-admissions, as do the Audit Commission, who cite the use of carer support workers in the Bristol Hospital Discharge Project as one means by which emergency re-admissions can be reduced (Audit Commission, 2004), and Carers England, who highlight the need for continuing support for carers if the re-admission of the patient is to be avoided (Carers England, 2002). Pearson et al (2004) recommend that support work needs to be carried out by someone who knows the patient and carer and their environment in order to break the cycle of discharge and admission.

2.4.3 Improving the rehabilitation/recovery of the cared-for person

Two studies which examined the effects of interventions with carers of stroke patients both collected some data concerning the recovery of the stroke survivor (Dennis et al, 1997 and Kalra et al, 2004). Dennis et al did not find any significant differences in physical outcomes between those patients who had received support from a stroke family worker and those who had not but surprisingly, those in the intervention group were found to be more depressed. They were, however, significantly more satisfied with certain aspects of their care, particularly communication and support. In contrast, Kalra et al reported that patients whose carer had received training had a significantly improved quality of life and mood outcomes at both three months and six months after discharge, compared to those in the control group.

In Pearson et al’s research, carers highlighted the inadequacy of the environment in which patients were expected to recover; hospital was purposeful but once at home carers felt isolated and unsupported (2004). In a case study of a patient’s rehabilitation after surgery, the author suggests that in order for rehabilitation to be successful, there must be multidisciplinary working (the team to include the patient and carer) and continued quality communication between acute and community services, patients and
their carers. The use of a discharge co-ordinator may also help to reduce problems in the patient after discharge (O’Connor, 2003). The Stroke Association’s report, looking at the role of information-giving for stroke survivors when they leave hospital, also highlights the importance of good communication between professionals and patients/carers in facilitating the recovery of the patient after discharge. They suggest that stroke survivors and their carers need more information and that meeting this need can positively affect recovery, particularly in the area of emotional well-being. The report indicates that patients and carers feel inadequately informed and that this can lead to misconception, anxiety and fear. It is recommended that stroke survivors and their carers are given information on the condition itself, how to reduce risks, services available, support for carers and contact details for voluntary organisations (Stroke Association, 2006).

2.4.4 Improving the carer’s experience of the process of discharge
Although there is little in the way of evidence for specific interventions affecting the carer’s experience of the process of discharge, a few studies in this review evaluated carers’ views on their experiences of hospital discharge.

Heaton et al (1999) describe a number of ways in which carers indicated that the process of discharge could be improved. Positive aspects of discharge practice were seen as provision of written and verbal information, carers’ attendance at case conferences, informal consultations with staff, training in care-giving, participation in home assessments and employing a practice of ‘phased discharge’. Effective discharge was seen by carers as being “contingent on how well they were involved during the discharge planning process” (p.93). Some carers in the study thought that they should have been more proactive in asking for information and training. The authors believe this finding suggests that, from the carers’ perspective, there is scope for improving the depth of their involvement, but more vulnerable carers may be disadvantaged if they are unable to take on this more proactive role.

Henwood (1998) found that some carers felt deliberately excluded from discussions about discharge and were not actively involved in decision making. This may have been because hospital staff lacked awareness of the role of the carer and the importance of involving them in the discharge process. Other studies have highlighted the dissatisfaction carers feel about the amount of information given during discharge and their lack of involvement. Davies (2000) found that carers were discontented because they did not feel they were given enough information or involved enough in the process. Carers were found to be less happy than the patients themselves about the amount of information given. In Shepherd’s examination of older people’s and their carers’ experience of discharge, almost one third of the carers interviewed described having little or no information or communication with practitioners, not only about discharge arrangements, but also about basic knowledge on how to contact professionals and services involved in the patient’s care (Shepherd, 1996). Shepherd comments that empowering users and carers to become involved in their care remains a challenge for professionals dealing with hospital discharge, but that the use of information packs which would be tailored to the patient’s and carer’s needs may be one way forward.

Not all groups of carers have the same experience of discharge. According to Holzhausen’s survey, older carers were much more likely to feel that they had been consulted about the discharge process, as did men (40% of men compared to 31% of women). Those from ethnic minorities, however, were less likely to be consulted (56% compared to 64%) and more likely to not have their concerns taken into account or be
involved in the planning process (Holzhausen, 2001). Overall, Holzhausen reported that 72% had poor experiences of discharge and only 28% had good experiences. Carers in this study made suggestions for improving the experience of discharge for carers. The top ten suggestions were:

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.

(Holzhausen, 2001, p.4)

In a study done for The Princess Royal Trust For Carers focussing on full-time carers (Warner and Wexler, 1998), it was also reported that older carers had the best experiences of hospital discharge. 70% of carers under the age of 64 said that they were not consulted before the patient was discharged from hospital. The authors surmise that older carers have health needs themselves and so professionals pay more attention to them. Horne (1998), whose report looked only at discharge arrangements for older people, indicated that most users and carers felt that they were kept informed about what was happening and planned, but the NAO suggests that there is “a concern from carers of older people (primarily family and friends) about the ways in which discharge is handled” (Comptroller and Auditor General, 2003, p.16).

The Audit Commission’s report into support for carers of older people found that only one of the six of the areas that were examined had a local carers’ strategy that properly covered carer involvement in discharge planning (Audit Commission, 2004). They recommend that all carers should be part of the discharge planning process for the people they care for and that NHS staff should routinely involve carers in the process – “carers’ own circumstances and needs should be skilfully identified and the future options available to them should be sensitively explored...” (p.65). The DH Change Agents Team suggests that the benefits of effective discharge planning for carers are that they feel valued as partners in the process, consider their knowledge has been used appropriately and are aware of their right to have their needs identified and met (DH, 2003). Carers England emphasise the importance of being open and honest with carers throughout the process of discharge and recommend that a realistic assessment of what will be involved in caring should be offered (2002). They see it as essential that carers should be seen as part of the team, as do Noyes and Lewis (2005), who also advocate the role of the ‘key worker’ in co-ordinating the discharge process. The extension of the multi-disciplinary team beyond the hospital boundaries to include community staff and social services can cause problems for carers (SSI, 1995). The SSI recommends that Local Authorities and Health Trusts should examine hospital
discharge procedures to ensure that all relevant parties collaborate in taking account of the needs of carers.

Longo and Scior (2004), in their exploration of users’ and carers’ views on in-patient psychiatric treatment for people with intellectual disabilities, suggest that carers’ experiences of the discharge process are mainly related to how good planning and support are around the time the cared-for person leaves hospital. If planning was poor and social support was lacking, carers were uncertain how to maintain progress and “sometimes experienced the discharge as an expulsion of the client from the in-patient setting” but, in contrast, if planning was seen as satisfactory, “carers appreciated the improvement in clients’ well being and any support provided” (p.218). In this study, carers were much happier with discharge planning if the patient was in a specialist setting as opposed to a generic one.

A few documents stress the importance of seeing the carer’s viewpoint if their experience of the discharge process is to be a positive one. Bull and Roberts (2001) emphasise the need for ongoing dialogue with carers so that they are happy with plans at all stages, and Brindle and Holmes (2005), in their discussion paper examining the issues involved when discharging patients with dementia from general hospital settings, recommend that carers must be consulted at all times and particularly when challenging decisions have to be made. In considering patients with dementia, their capacity is not always clear cut and so close attention should be paid to anxieties and concerns on the part of the carer. In situations where the patient’s capacity is not in question, the carers’ needs may be viewed mainly in relation to the patient’s assessment and not in and of themselves. If discharge planning is predominantly patient-centred then the patient, not necessarily intentionally, may act as an intermediary between professionals and carers and possibly reduce the involvement of the carer in the discharge process (Heaton et al, 1999). In line with other studies mentioned above, Heaton et al reported that many carers in their study were unhappy with the timing of discharge; carers often wanted patients to stay in longer than the patients themselves did. Shepherd (1996) reported that carers were much more likely than service users to voice dissatisfaction about experiences on the day of discharge concerning problems around carer involvement, communication, information-giving and the way decisions were made.

2.4.5 Enabling the carer to continue caring

The two RCTs looking at interventions with carers of stroke patients both collected data concerning outcomes for carers after the patient had been discharged home. In Kalra et al’s study, the results indicated that the burden of care was significantly reduced in the group who received carer training and also that quality of life and mood in these carers improved significantly at three months and 12 months post-discharge (Kalra et al, 2004). In the economic evaluation of this study, the authors comment that “improving the skills of consenting informal care givers during inpatient rehabilitation reduces stroke care costs and improves their quality of life without increasing the burden of care to families or transferring costs to the community” (Patel et al, 2004, p.1104). Hankey (2004), commenting on Kalra’s research, recommends that carers of stroke survivors must be as adequately trained, supported and followed as the patient. They should be part of the multi-disciplinary team and be actively involved in goal-setting and discharge planning. In their evaluation of a stroke family care worker, Dennis et al found that carers of patients in the intervention group had better outcomes than those in the control group; the differences were significant for mood symptoms and of borderline significance for anxiety and hassles (Dennis et al, 1997).
In studies where there were no interventions, however, many carers highlighted the lack of adequate arrangements to meet post-discharge needs. Henwood (1998) points out that “the transition from home to hospital can be a shock” and found that it was sometimes only when the patient returned home that the level of care need became apparent (pp.33-34). Carers were often left to cope with these needs alone and, particularly when the cared-for person’s needs were greater than before they went into hospital, carers often struggled to resume caring responsibilities after discharge. Henwood found that some people were left without necessary services for some length of time after discharge which caused stress for both carers and those that they cared for. She surmises that this may have been due to a lack of communication between hospital staff and community staff. In the follow-up study, over 40% of carers did not feel they were given sufficient help when they returned home (Holzhausen, 2001). In Negus’ description of the implementation of a new service for carers, one carer who benefitted from the carers’ specialist commented that “…it was particularly helpful after mum was discharged to discuss and sort out queries that just weren’t so obvious when she was in her hospital bed” (Negus, 2004, p.35).

Heaton et al also point to the difficulty of carers knowing what provision is required after discharge and emphasise the need for carers to be made aware of what is available to them. Some carers in the study though that a list of options (or ‘a menu’) of available services would be valuable, but it appeared that what was theoretically available was not always offered by professionals because services were stretched or limited (Heaton et al, 1999). This study also revealed needs that carers had but were not recognised during discharge planning; namely, follow-up in the community and recognition of the impact on other household members after discharge. The authors found that “the period immediately following discharge was found to be a difficult time for the carers in the study…” (p.98).

In Warner and Wexler’s survey, respondents were asked if, in their experience, nobody asked the carer if they could cope at home before discharging the patient. Almost half said that they ‘strongly’ agreed with the statement and a further 19% ‘slightly’ agreed. Female carers were more likely to agree with the statement which the authors believe suggests that the medical profession may tend to assume women will be more able to cope than men (Warner and Wexler, 1998).

In Shepherd’s research into the discharge experiences of older people and their carers (1996), 41% of carers described difficulties in coping after the cared-for person left hospital. In half of these cases, the user did not share the concerns of the carer. This again emphasises the difficulty of balancing carer views with those of the cared-for person. Over half the carers expressed dissatisfaction with the services they received at home after discharge and one third had specific difficulties in relation to equipment. For some, this was because equipment had not been in place by the time the older person returned home and for others there was a discrepancy between what the carer wanted and what the cared-for person thought was necessary. One carer highlighted the need for carers to be consulted (Shepherd, 1996).

Proctor et al (2001) again draw attention to the need to see the carer’s point of view and not to assume that they are able or willing to care. They comment that it is difficult for individuals, either carers or professionals, to challenge the obligations associated with the role of carer once a person has been defined as such by either the patient or the professionals. If the carer does not conform to professional expectations, carers sensed that “those professionals questioned their moral integrity, thus creating a highly coercive environment within which care is given and received” (p.213). From the same study, Pearson et al (2004) found that carers saw themselves as a ‘barrier’ to assessing...
patients’ needs, in that there was an assumption on the part of professionals that the
carer would be able to take on care after discharge. Carers also felt that they lacked
information and support in their role.

Horne (1998) stresses the importance of carer assessment in relation to enabling the
carer to continue, or commence, caring. In his report for the Department of Health, it
was found that assessments of the carer’s ability to care “rarely took place”, but that
sometimes this was partly to do with carers being reluctant to take up the option for
assessment. Horne recommends that more should be done to highlight the benefits
that can be achieved (both to carers and staff) through assessment and that
professionals need to be sure that carers are aware of the option for assessment.

Carers UK (2003) also point to the importance of carers being made aware of their
right to assessment in their own right by hospital staff, particularly when facing the caring role
for the first time. They also need to be informed about how to access services, such as
social care, after discharge.

The value of effective discharge planning in helping carers to continue (or start) their
caring role is emphasised by the DH’s good practice guide for hospital discharge (DH,
2003). It can help carers to feel confident of continued support and get help before they
have problems, have the right information and advice to help them in their caring role,
feel that they have been given a choice about undertaking the role of carer and
understand what has happened and who to contact. The authors comment that “with
adequate support, carers will often be willing to take on or continue with a caring role”
but should be given time to consider their options (p.4). The Audit Commission (2004)
also advocate planning and carer assessment in order to facilitate a successful
discharge. They indicate that “serious consideration should be given to providing some
short-term support to any carer involved” in the discharge of an older person (p.64).

2.5 Summary

Many of the main themes from the ‘Policy Background’ section can also be seen in the
‘Findings’ sections. Areas for consideration can be summarised as follows:

- the need for communication with and involvement of carers at all stages of the
discharge process
- the importance of acknowledging carers’ needs and their right to an assessment
- the recognition that the carer’s views and wishes are not always the same as those
  of the cared-for person and the need to consider how to balance the two
- the potential value of the carers’ specialist/key worker role
- the importance of ensuring that carers are fully aware of the options available to
  them
- the benefits of ongoing support and follow-up for the carer, both pre- and post-
discharge
- consideration of the timing of discharge and whether the carer is fully involved in the
decision-making process concerning when the cared-for person leaves hospital
- a recognition that poor discharge planning can lead to stress and anxiety in the
  patient and carer, a possible reduction in the carer’s ability to care and potential un-
planned re-admissions
• the advantages to both the patient and the carer of the involvement of, and participation in, the multi-disciplinary team
• the potential value of training for carers
• the necessity of encouraging communication across health and social care
• the need for increased awareness of the carer role amongst hospital staff.
Chapter 3
Mapping Exercise

Fifty-one of the 87 Carers’ Centres in England returned a completed questionnaire, giving a response rate of almost 60%. Nineteen of the centres responding reported that they provided a service designed to support carers when the person they cared for was being discharged from hospital. A further 22 centres noted that they had plans to develop targeted services but these plans were at very varied stages of development/progress. Some had secured funding and were able to give a projected start date (mainly within the coming year), while others specifically stated that the development of the service was dependent on obtaining funding. Many of the other centres noted that although they did not have dedicated services, their core services did provide support to carers around hospital discharge.

3.1 Profile of Current Services

3.1.1 The aims of the service
Centres were asked to provide a brief description of any services/projects they run or contribute to which are designed to support carers when the person they care for is being discharged from hospital. Some respondents described the nature of the service provided (e.g. “Carers Support Worker spends an afternoon a week walking around the wards talking to carers that have been identified by hospital staff as needing our support”), while others talked more about the objectives of the service (e.g. “raising carer awareness in the hospital”). For this reason we decided to use the information provided to examine the main aims or purpose of the services rather than attempt to describe the different types of services provided in detail. Five main ‘aims’ emerged, with services often having several aims.

Identification and signposting of carers – seven centres said that their service was intended to improve the identification of carers when the cared for person was in hospital. Some did this by carer’s workers attending discharge meetings and visiting wards, while others worked with hospital staff (including hospital based social services staff) to encourage them to identify and refer carers to the carers centre. Two services carried out Carers Assessment on behalf of the local authority. Some services then signposted carers to existing services which could help them (e.g. other services provided by the carers centre, benefits advice etc), while others were able to offer direct support and advice (see below).

Direct support and advice to the carer – nine centres offered direct support and advice to carers, including emotional support, practical help with issues such as benefits, advocating on behalf of the carer and ensuring appropriate services are put in place. Five centres noted that they provided post discharge follow-up either request or routinely at a set point (e.g. follow-up phone call 6 weeks post discharge).

Training for carers – only one centre described providing training for carers around the time of hospital discharge. However, it is possible that carers signposted to other services were able to access general carers training.

Provision of information - another important aim for several services (6) was the provision of information for carers, often in the form of information packs, leaflets or posters displayed on hospital wards. Respondents reported that the type of information
given included advice about how to get help, details of the services and support available to carers locally, explaining carers rights and entitlements.

**Raising awareness and changing systems** - eight centres reported that one of the aims of their service was to raise awareness amongst hospital staff of carers’ issues and the benefits of supporting carers through the discharge process. For a few centres awareness raising was the primary purpose of the service - as one centre put it “the project aims to develop systems and resources for staff to fulfil their responsibilities to carers and create a culture of carer awareness”. Centres noted that they were using a variety of approaches to achieve this change, including staff training, the development of referral protocols, changes to discharge paperwork, the creation of ‘carers leads’ on key wards, and the development of a carers charter. For others, increased awareness of carers issues was a by-product of their engagement with hospital staff. For example they saw making regular visits to wards or attending discharge meetings as both a means of identifying carers needing support and of improving the understanding of carers’ issues amongst hospital staff.

3.1.2 **Which groups of carers the services/ projects are intended to support**

The carers’ centres were asked whether the service was designed to support any particular group. Many had an open service available to any carer of any patient using acute care in their area. However, some services were designed to target particular groups including four targeted on carers of people who have had a stroke and two for carers of patients with extra needs (e.g. people with physical disabilities or the frail elderly). One centre reported that its service was only open to carers of adult patients and another that the service did not cover young carers.

3.1.3 **Organisation and Funding**

The majority of services were being run by the carers’ centres themselves (15). Two were run by the carers’ centre jointly with the hospital Trust, one was run by the county council and the PCT and another by the PCT. Half the services had been running for more than two years, including one service established in 2000.

The centres were asked to give brief information about how their service was funded and seventeen of the 19 centres provided this. For several centres (9), funding had come from more than one source. As described by one centre manager described it - “a cocktail of funding from local authority, hospital trust and carers centre”. The pie chart below shows the main sources of funding.

**Figure 1 Sources of funding for specialist discharge services**
The most common source of funding was the local authority (13), which included funding from the carers’ special grant. Eight centres received funding from the NHS (either PCTs or Acute Trusts) and a further three mentioned grants from the lottery (2) and The Princess Royal Trust For Carers (1). Three centres were sourcing at least some of the funding for their service from ‘internal’ funds already assigned to their general ‘pot’.

3.1.4 What has been the perceived impact of this service?
The centres were asked what, in their view, had been the impact of their service on:

- Avoiding delayed discharge
- Reducing admission rates for the cared for people
- Improving the rehabilitation/recovery of the cared for person
- Improving the carer’s experience
- Enabling the carer to continue caring

They were given the following options - significant impact; moderate impact; minimal impact; no impact or; not applicable (N/A)

Although the findings shown in Figure 3 are based on self assessment rather than any hard measures of the impact these services, they do provide a useful overview and suggest that the main observed impact has been on improving the carer’s experience and enabling the carer to continue caring, rather than on avoiding delayed discharges and reducing admission rates which are much harder for centres to assess.

Figure 3 Ratings the impact of the service
3.1.5 **Evaluation of the service**
Of the 19 services described, only two had been evaluated externally, six had been evaluated internally and ten reported not having carried out any form of evaluation to date (one centre noted that their service had been evaluated internally and externally).

3.2 **Overview of Proposed Services**
The centres were asked if they were planning to develop any new services designed to support carers when the person they care for is being discharged from hospital. Just under half (22) of the centres responding had plans to set up such a service (although one was an extension of an existing service). Those that had a planned date for the service to be up and running gave dates within the next year; five reported that they did not know when the service up and running and; five said that the initiation of the service was dependent on securing funding.

Perhaps not surprisingly, the main aims of the proposed services mirrored those of the existing services described above, and again, some proposed services had more than one aim. The identification and signposting of carers and the provision of direct support and advice to carers were again key aims for several centres, but only one centre said that they intended to offer carer training. Interestingly, proportionately fewer centres (3) said that they intended to provide information in the form of packs and leaflets available in the hospital, while a greater proportion (9 centres) listed raising awareness of carers issues and/or changing systems as a key aim of their proposed service. Again, one centre noted that they were trying to agree ‘carer standards’ in relation to discharge with colleagues in health.

3.3 **Wider Services**
All the centres were asked whether they provide any wider services which help to support carers when the person they care for is being discharged from hospital. The main services provided were direct support and information, although some centres were also providing advocacy, undertaking carer training and working with hospitals and PCTs to increasing awareness of carers’ issues. As might be expected the direct support, which was being offered by 31 centres included emotional support, often in the form of counselling, advice and help with financial matters including benefit applications, and practical help with things like aids and adaptations, transport problems etc.

Twenty-three centres reported providing information/advice to carers. They used a variety of approaches to disseminating information including leaflets, newsletters, information packs, information days, telephone helpline. Some centres also noted that they had information workers and/or ran carers’ forum where people could access or exchange information. The purpose of the information provided covered welfare rights, signposting to other service, information on hospital discharge policy, information about practical aspects of caring (e.g. back care/moving and handling) and information relevant to the condition or care group of the cared for person.

Three centres reported providing services targeted at raising the profile of carers. Whilst two were focused on raising awareness within hospitals to improve the hospital discharge process through greater involvement of carers, one centre was targeting GPs
and their practice staff to encourage them to improve support to the carer immediately post discharge. Lastly four centres noted that they were working to improve links with health and social care services with the aim of encouraging them to refer carers to the centre.

More generally, several of the centres who responded highlighted the importance of services for carers at point of hospital discharge, saying for example “There is a massive need to reach carers visiting hospitals”. Unfortunately, respondents also acknowledged that the development of services was hindered by lack of funding, with one centre noting - “The current crisis re NHS finances has resulted in no development funding being available, particularly in secondary/acute care.”

Those who had been able to run this type of service reported that they had had positive feedback about their service, while others were finding that progress in this area was not being made as quickly as hoped. As one respondent put it:

“Although hospital discharge groups are aware of [the service] and carers support, very few referrals came through this route. Carers are not always receptive to information given to them.”
Chapter 4
Conclusions and Recommendations

The literature review revealed that there is very little primary research which evaluates specific interventions to support carers during the process of the cared-for person being discharged from hospital. Of the 18 primary research studies considered relevant to the present report, only five actually involved an intervention and none of these were aimed directly at the discharge process as it related to carers. The majority of the remaining research documents examined patients’ and/or carers’ views on the process of discharge. The messages which emerge from this body of research about what principles and practices might lead to effective support for carers at the time of discharge, and what policy makers expect from organisations working with carers, are relatively clear and consistent. In particular the literature suggests the need for:

- **High levels of carer awareness amongst hospital staff** – This might be achieved in many different ways (staff induction and training; designating a ‘carers’ lead’ for each ward; joint work between carers’ workers and ward staff; the creation of a carers’ charter setting out the hospital’s responsibilities to carers) but it has to be there or all other initiatives to support carers are likely to be less effective because carers will not be recognised, recorded and referred.

- **Policies and procedures which recognise carers** – Whilst carer awareness is the foundation of good support, it needs to be reinforced by policies and procedures which emphasise the importance of involving carers in the discharge process at an early stage, acknowledge their needs and rights, and then enable staff to record carers details. These policies and procedures might include discharge policies developed in conjunction with the local carers centre; paper and electronic recording systems which encourage and enable staff to record carers’ details and wishes: and referral protocols which clearly identify the involvement of a carer.

- **Easy access to information and signposting of carers** – The provision of accessible and timely information, together with systems for signposting carers to sources of help and advice, can clearly make the discharge process easier, especially for new carers. Again there are many ways to achieve this, including leaflets and posters, information packs, and carers’ advice surgeries held in the hospital, but all of them are likely to be more successful if they are accompanied by high levels of carer awareness and the right policies and procedures.

- **Direct support and advice to carers** – Support and advice can be provided in many different ways, but the literature indicates that two ‘interventions’ may be particularly helpful – i) access to a specialist carers’ worker who can provide, or ensure that carers get access to, practical and emotional support both pre- and post-discharge and ii) training for carers prior to the cared-for person being discharged.

Whilst the mapping exercise showed that several centres have tried to put in place services and/or initiatives designed to make these principles and practices a reality, in many areas there is still a gap between what policy and research says should happen and what actually happens to carers as the person they care for passes through the hospital system. Even where services and initiatives to support carers through the discharge process exist, there is only limited evidence from research or evaluation to demonstrate their impact on the carer’s experience, and even less evidence which shows that such support can:
• ensure discharge takes place at the appropriate time;
• reduce re-admission rates and;
• improve the rehabilitation or recovery of the person being cared for.

It is with these findings in mind that The Princess Royal Trust for Carers has decided to focus Stage Two of the *Out of Hospital Project* on the evaluation of initiatives which are designed to influence procedures and practice in hospital discharge. A full report from Stage Two will be available in summer 2009.
References

Community Care (Delayed Discharges etc.) Act (2003). Crown copyright.
Princess Royal Trust for Carers 'Out of Hospital' Project – Report from Stage 1 June 2007


Appendix 1 - Search Strategy

1. Aims of the Review
The review will address two key questions:

- What is known from the existing literature about the provision of services to support carers during the process of the cared for person being discharged from hospital?
- What is known from the existing literature about the effectiveness of services to support carers during the process of the cared for person being discharged from hospital, in particular in relation to:
  - Avoiding delayed discharges
  - Reducing readmission rates for those being cared for
  - Improving the rehabilitation/recovery of the cared for person
  - Improving the carer’s experience of the process of discharge
  - Enabling the carer to continue caring

2. Geographical and Language Restrictions
Only literature relating to the UK and published in English will be included.

3. Date Restrictions
Only literature published since 1995 will be included. This is because any literature published prior to that date would not reflect the changes in the health and social care system and the legal rights of carers brought about the NHS and Community Care 199? And the Carers Recognition and Services Act 1995.

4. Search Terms
Two combinations will be used - carers and hospital discharge and carers and hospital. Words will be truncated as appropriate and the searches will be conducted on the title, abstract and key words.

5. Types of Documents Included
- Journal articles
- Research reports
- Books
- Grey literature
- Research in progress
- Policy documents
6. Electronic Databases and Websites Searched

Time and resource constraints mean that the number of databases to be searched will be limited to:

- CSA (ASSIA: Social Services Abstracts; Sociological Abstracts)
- Social Policy and Practice (via OVID)
- Social Care Online
- Age Info
- CINAHL/EBSCO Academic Search Elite
- Medline
- British Library Online
- Centre for Reviews and Dissemination (DARE; NHS EED; HTA)
- Google Scholar

The websites to be searched will include:

- Department of Health (www.doh.gov.uk)
- Carers Information (www.carersinformation.org.uk)
- National Research Register (www.nrr.nhs.uk)
- Intute (www.intute.ac.uk)
- National Library for Health (www.library.nhs.uk)

Some limited checking of the bibliographies from published studies may be undertaken, and additional relevant documents may be tracked down if they appear to be particularly relevant.

7. Quality Appraisal

As this is a scoping study, intended to map the literature (including grey literature) in this field, and support and inform the second phase of the research, we do not intend to undertake formal quality appraisal of the documents included.
Appendix 2 - Survey Form

Out of Hospital Research Project
Survey of Carers Centres

Contact Details

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1. Does your Centre have any services/projects (or contribute to any services/projects run by another organisation) designed to support carers when the person they care for is being discharged from hospital? (please tick)

   Yes   No

   If Yes, go to question 2. If No, go to question 9.

2. When was the service/project(s) established?

   

3. How is the service/project(s) funded?

   

Out of Hospital Survey – March 2007
4 Which groups of carers is the service/project(s) intended to support?

5 If the service/project is run by another organisation(s) (e.g. a PCT, Hospital Trust or voluntary sector organisation) please provide details in the box below.

6 Please give a brief description of the service/project(s) in the box below:

If you have any information about the service/project (e.g. leaflet for carers or professionals) or supporting documents (e.g. job description or referral protocol) which you think the research team would find helpful, please enclose them when you return your survey form.

7 In your view, what has been the impact of the service/project on: (please tick)

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<th>Not Applicable</th>
<th>Significant Impact</th>
<th>Moderate Impact</th>
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<td>Avoiding delayed discharges</td>
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<td>Improving the carer's experience</td>
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<td>Enabling the carer to continue caring</td>
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</table>
8 Has the service/project been evaluated? (please tick)

- Yes - by an external evaluator
- Yes - internally by centre staff
- No evaluation

*If there a report from the evaluation available, please could you enclose this when you return your survey form.*

9 Is your Centre planning to develop any new services/projects designed to support carers when the person they care for is being discharged from hospital? (please tick)

- Yes
- No

10 If Yes, when do you hope to have these services/project up and running?

11 Please give a brief description of the planned service/project(s) in the box below:

12 Does your Centre have other wider services/projects which help to support carers when the person they care for is being discharged from hospital?

*If yes, please describe these briefly the box below.*
Do you have any other information or comments you would like to add?

Finally, as part of the project, we are undertaking a review of UK published and unpublished literature relating to carers and hospital discharge. If you know of any unpublished reports (e.g. local studies or evaluations) which you think the research team should include in the literature review, please can you provide details below, including (if possible) where we could obtain a copy of the report.

Many thanks for taking the time to help us with this survey

Please return your survey form (plus any supporting papers) by Thursday 12 April if possible in the prepaid envelope enclosed to:

Acton Shapiro, School Lane, Greengate, Malton, York YO17 7EL

or

If you are completing the survey electronically, please email it to:

liz@actonshapiro.co.uk
Appendix 3 - Documents not obtained


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