



# CARERS AS PARTNERS IN HOSPITAL DISCHARGE

- Improving carer recognition, support and outcomes  
within timely and supported discharge processes

## A REVIEW

February 2010

### **Please Note**

This review is intended to be a contribution to debate. Whilst every attempt has been made to ensure accuracy and promote best practice, the content of this document does not represent a formal statement of the law or Government policy. The Association cannot accept any responsibility for loss or liability occasioned as a result of people acting or not acting on information contained in this paper.

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Should any conflict or apparent difference in interpretation arise in relation to current statutory or accepted best practice guidance, the expectation is that the statutory guidance would take precedence.

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## FOREWORD

This short review forms part of our programme of work in 2009/10 to take forward the implementation of the cross government strategy for carers [1]. One of the key outcomes for 2018 we are working hard to support is that:

*“carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role.”*

In his Foreword to the best practice guide **“Transforming Community Services: Ambition, Action, Achievement”** [2] Lord Darzi offers us all a powerful reminder that what happens to people in hospital is only part of their story. He says:

*“People live out their lives in their own homes and communities. It is here that their health and well being is shaped by the circumstances in which they find themselves”*

Discharge from hospital is a process and not an isolated event. It begins with admission and all parts of the system [family, carers, hospitals, primary and community care services] should be working together to assure quality experience for patients and carers. The importance of identification, assessment and support of carers as expert partners in hospital discharge is well recognised. The key question raised by this short paper, however, is:

*Why is it, when we have so much good policy and practice advice to guide us across this care pathway, that some carers still feel unrecognised; say they are not treated as partners and processes don't work as well as they might for them and the person they support?*

If we are to see improvement we need to learn from the best. More systematic feedback is needed to change organisational cultures, promote organisational learning and drive up consistency and quality of experience. At our workshop we saw how one Acute NHS Trust was beginning to tackle some of these challenges. Together, we have identified twelve key themes for improvement and for further work to help make the vision of **carers as partners in hospital discharge** a reality.

We all need to do more to ensure action throughout the discharge pathway reflects a better understanding of the impacts on carers and the need for better overall outcomes for carers and the cared for person. There are many common themes but also specific issues for carers from black and minority ethnic groups, carers of people with dementia and for “young carers”. Information and advice in support of carers’ and patients’ rights and exercise of choice and control are often critical. If carers and the people they support are informed, involved and supported along the care pathway the likelihood of good outcomes rises, risk of readmission falls and the financial and emotional costs this incurs avoided.

Quality is and has to be the guiding principle across more personalised health and social care pathways. By concentrating on quality experiences, we can reduce variations in service and in outcomes. We believe front line staff, carers and patients all have a real contribution to make in improving hospital discharge in partnership with one another. Local clinical and management leadership is equally vital if we are to achieve the ambitions of the national strategy around partnership with carers.



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## TWELVE KEY MESSAGES FROM THIS REVIEW

The overall message is that whilst there is good practice and progress in some places, there is still a continuing need to change attitudes and cultures and to better understand their impact on carers. If health and social care are to work with **carers as partners in hospital discharge** we should work together to ensure:

- Clinical and managerial ownership and leadership
- All statutory services have a lead on carers
- Specialist support is available for people with dementia
- Carers' issues are embedded into training and organisational cultures
- Information for carers is accessible and available
- Services understand better the needs of black and minority ethnic carers
- Feedback and learning from initial discharge experience is improved
- Operational cultures support carers as **partners in caring**
- Everywhere is as good as the best on hospital discharge
- Discharge pathways are seen in their community context
- Parents and young carers are supported and avoid inappropriate caring roles
- Progress is kept under review and recognised

In summary, we need to keep a strong focus on the outcomes we are seeking for carers and the person cared for within the hospital discharge process and on return home, and to be confident they are being delivered in practice. As Emily Holzhausen of Carers UK said during the course of this review:

*My experience of working closely with some front line workers is that although they are excellent staff they don't always really understand the impact of their decision making on carers. It is really telling sometimes and I hope that with each step we take together, like this review, we can continue to change this. I'm sure it will lead to better outcomes for everyone if we are able to do so.*

# 1. INTRODUCTION

## Background

Achieving timely and appropriate hospital discharge has been one of the key aims of the community care agenda. There has been a strong emphasis on agencies working together across traditional organisational boundaries and in partnership with patients and carers. Going into and coming out of hospital, however, can be an uncertain and sometimes emotional experience for people and their families or friends. For some, it is a life changing event requiring major adjustments afterwards.

The processes and practices for achieving better outcomes that promote capacity for independent living are set out in best practice guidance issued in 2003: ***“Discharge from hospital: pathway, process and practice”***[3]. This guidance updated and built on the earlier Hospital Discharge Workbook issued in 1994. Hospital discharge is a process and not an event. A number of potential contributors to difficulties in achieving timely, safe and appropriate hospital discharge for patients and their carers were identified. They were:

- Internal hospital factors
- Co-ordination issues within and between agencies
- Capacity and resource issues
- Patient/carer involvement and choice issues

Choice and involvement issues are invariably linked to the factors listed above. Weaknesses in one area, for example, lack of co-ordination or winter pressures can impact on capacity. This in turn can impact on the patient and carer experience. This short paper seeks to explore issues around involvement and choice and improved recognition and support for carers as partners within the hospital discharge process. The focus is on learning: it is not about one part of the care pathway criticising another and there are messages about listening and learning for all of us.

## Methodology

This paper came about as a result of concerns around the scope to further improve recognition and support of carers as partners within hospital discharge processes. The intention has been to explore potential for improved partnership working and better outcomes for both the carer and the patient who becomes the cared for person on discharge. To do this we:

- carried out a web based literature search [ See: sources and references];
- discussed matters with stakeholders and ADASS Carers Reference Group;
- linked into specific projects, research programmes and reports;
- discussed thinking with the Carers and Hospital Discharge social care leads within Warwickshire County Council;
- held an invitation day workshop in London involving people across health, social care and carer organisations; and,
- used an iterative drafting process to clarify thinking, develop ideas and engage stakeholders on what might be done.

## 2. OVERALL CONTEXT

Most people who leave hospital do not need any long term support. Some do. Help may be needed for the first few weeks or, in some cases, for a longer period from a carer or care agencies. For some it will be for the remainder of their life.

In general terms hospital discharges fall into two main groupings: simple and complex. Effective hospital discharges can only be achieved where there is effective joint working between agencies and with the genuine involvement of patients and carers [3] [4]. Carers are key partners within the hospital discharge process.

It is not intended to reproduce here all the policy and practice advice that has been in place for some time. The key messages from the Foreword to the 2003 “good practice” guidance are reproduced as **Appendix A**. The intention of including this and other materials is to provide both a reminder and easy access to some of the key information that informs what happens around carers and the hospital discharge process. It is hoped this will facilitate discussion of issues outlined in this review.

The 2003 material offers a number of practical tools to help agencies tackle areas of challenge around pathways, process and practice necessary to achieve improved outcomes and meet performance targets. Subsequent guidance issued in 2004 [5] **“Achieving timely ‘simple’ discharge from hospital”** also emphasises that what happens during the discharge process is a key part of the patient’s experience of hospital care. Some hospitals have developed “simple” discharge toolkits to support this discharge pathway [6] [7].

Most hospital discharges fall into the “simple discharge” category. It is always useful to keep in mind, however, that what may be a regular or routine process for professionals may be a “first time” or stressful transition for carers and patients that can be full of uncertainties and unknowns. Three key points [5] are made about making the guidance work. All are relevant to carer experience within it. They are:

- Achieving change depends on winning hearts and minds as much as convincing with rational arguments.
- The key to success is to tackle both cultural change and changes to process and organisational systems.
- Services will be more effective if everyone has a better understanding of the whole health and social care system and of how actions and changes in one area can influence the whole system. [p14]

**High quality care for all**, 2008, [8] makes clear that quality is about safety, efficiency and patient experience. High quality and best use of resources are not seen as competing alternatives but as one and the same thing. They are integral to timely and supported hospital discharge and should be part of our thinking.

**The NHS Operating Framework for 2009/10** [9] set out the priorities and how this vision can be delivered. It reflects the shift from a top down process to:

*“... more devolved ownership so that services are increasingly developed by front line staff around the needs of local populations.” [p7].*

It emphasises the importance of personalised service and patient centred care that:

*“...means organising services around patients, meeting their clinical need, working in partnership and treating them with dignity and respect.” [p23].*

The **NHS Operating Framework 2009/2010** [\*] confirms the commitment that;

*“... delayed transfers of care are expected to be maintained at a minimal level”.*

Data on delayed transfers and timeliness of social care assessments and care packages continue to form part of the “vital signs” for delivery of personalised and effective care [p.47].

In the Foreword to this review we note Lord Darzi’s powerful reminder [2] that what happens to people in hospital is only part of their story. It is especially relevant to the position of carers and bears repetition here:

*“People live out their lives in their own homes and communities. It is here that their health and well being is shaped by the circumstances in which they find themselves”*

This thinking should inform hospital discharge processes and help to focus attention on factors that may reduce risk of delay, breakdown at home or readmission. It reminds us that the recognition and support available to carers and positive experiences within the wider care pathway are closely interlinked. A number of the proposals made in relation to community services have a resonance with improving carer experience. They are about assuring consistent and quality care experiences and ensuring awareness of local carers’ strategies along with:

*“... providing all carers with a holistic assessment in their own right and giving the appropriate information, support and advice...”[ and later to] “...include patients, families and carers as essential and knowledgeable members of the care team to promote confidence that care can be managed outside hospitals.”*

Other areas encourage a focus on:

- Creating effective partnerships
- Developing creative approaches
- Providing patients and carers with a named key worker

Finally, we have linked this review to the approach outlined in the new national strategy “**Living well with dementia**” [10] published in 2009. This was an important step forward and the strategy identifies a number of areas for improvement and this includes the experience of carers and the person with dementia being cared for. The issues around hospital discharge are considered in Section 5 [page 18] of this review.

[\*] The Operating Framework for the NHS in England 2010/11 was published on 16 December 2009 and this expectation continues to be in place.

### 3. INVOLVED & INFORMED CARERS

#### Involvement of Carers as Partners

The key principles [3] for effective discharge and transfer of care outlined in the best practice guidance are set out in **Appendix B**. The expected outcomes or benefits of effective discharge planning for patients and carers are stated to be:

*“For the patient:*

- *needs are met;*
- *able to maximise independence;*
- *feel part of the care process; an active partner and not disempowered;*
- *do not experience unnecessary gaps or duplication of effort;*
- *understand and sign up to the care plan*
- *experience care as a coherent pathway, not a series of unrelated activities*
- *believe they have been supported and have made the right decision about their future care;*

*For the carer:*

- *feel valued as partners in the discharge process;*
- *consider their knowledge has been used appropriately;*
- *are aware of their right to have needs identified and met*
- *feel confident of continued support in their caring role and get support before it becomes a problem;*
- *have the right information and advice to help them in their caring role;*
- *are given a choice about undertaking their caring role;*
- *understand what has happened and who to contact;” [Page 3-4]*

Chapter 4 of the 2003 guidance confirms that:

*“The engagement and active participation of individuals and their carer[s] as equal partners are central to the delivery of care and in the planning of a successful discharge.”*

The Department of Health guidance also recognises that establishing a clear and common understanding of person centred care inherent in this principle is not without difficulties. The need for recognition of carers is confirmed. It is made clear that this is about the active involvement of patients and carers and not:

*“... just keeping the patient informed and up to date with decisions about their care as passive players in the process.”*

In short the agenda is one of partnership in hospital discharge. The guidance [3] reproduces a part of a hospital discharge guide published by Carers UK. A slightly different good practice checklist from the Hospital Discharge Practice Briefing [2003] [11] and is reproduced as **Appendix D**. Consistent with this guidance, some hospitals have developed carers’ policies and guidelines. Two examples we have reviewed are: University College London Hospitals NHS Foundation Trust [12] and Homerton University Hospital NHS Foundation Trust.13]

## Information for Carers

Material from the 2003 guidance [3] has found expression in a variety of leaflets designed to improve support for carers during the process of hospital admission and discharge. Examples include:

- MS Society, Guidance for Carers: Hospital Discharge [14]
- Durham, Is someone close to you coming out of hospital? [15]
- Camden, What to do when the person you care for goes into or comes out of hospital [16]
- Surrey, Hospital Discharge: the carer's journey [17]
- Carers UK, Coming out of hospital, a guide for carers, [18]

Organisations such as Counsel and Care [19] and Age Concern [20] have produced wider materials. These are designed to help patients and carers get more information; to feel more in control and to make more informed choices about future care and support where needed. Carers also need information to help them to reduce risk of physical injury or stress arising as a result of their caring role. Back care is a key area. In Devon, for example, there is a fact sheet [21] designed to help carers find support and advice.

The British Medical Association (BMA) has recognised [22] that:

*“... many of the physical injuries could be prevented if carers received some training in how to move the person they are caring for in a safe and effective way. This can be particularly important at the start of caring.”* p.8

Professionals have an important role in this respect and in growing an understanding that carers need to think about their own needs as well and not wait until a crisis. The BMA included the following areas where programmes of support and learning could be helpful:

- Moving and handling
- Relevant nursing skills
- Use of equipment
- Continence care
- Stress management
- Helping carers to look after themselves

**Caring with Confidence** [23] is a key part of the new national strategy for carers and is a valuable resource for carers. It is a free service that offers information, learning and development opportunities to help carers build on their existing skills and knowledge and to explore their feelings through local workgroups or on line.

## Information Sharing

Information around admission, hospital stay and discharge falls into three broad groupings or functions:

- Information about the support and follow up available on discharge for the carer and the patient; including the practicalities of the process, timing, medication, rights to assessment etc.
- Personal and often sensitive information relating to the individual patient about the diagnosis, prognosis and treatment and management both in hospital and afterwards.
- Partnership information that enables the carer to perform their future role safely and with the necessary skills and knowledge to make informed choices about capacity to meet the needs of the patient who becomes the person cared for both on discharge and over time.

Information sharing and confidentiality have been identified by carers as an area that can be problematic. Information about patients is gained and retained under a duty of confidence. Sharing this information needs to meet legal requirements on confidentiality and, where it takes place, the *best interests* of the patient need to be kept firmly in mind. Patient understanding and capacity for consent to information sharing and any views about what can and cannot be shared with families and carers is critical.

Families and carers do not have an automatic right to receive information about the person they care for. It makes considerable sense, however, to work positively with them and actively inform, include and empower them [e.g., knowing what to ask about and what they may be entitled to]. This should be consistent with the caring roles and responsibilities undertaken prior to admission or may be expected on discharge and take account of the wishes of the patient.

### **Information Sharing and Mental Health**

A briefing paper [24] issued in January 2006 outlined good practice for service providers on information sharing. We are aware through feedback of continuing concerns of carers around information sharing in the area of mental health. As one mental health trust [25] has indicated:

*“ The rules of confidentiality must not be used by staff as a means of excluding family members and carers. There is a lot of very important information which staff can provide to help families and carers understand the needs for their cared for person and their own needs as a carer. This type of information can be provided without releasing information about the patient and breaching confidence”*

This and other Trusts have recognised [26] [27] that carers will also have knowledge and information that may be helpful to staff in understanding and responding to patients' needs. The *Partners in Care* programme produced valuable materials to guide discussion and disclosure [28] in ways respectful of the different rights and responsibilities of those involved. Information plays a valuable role in shaping the quality of experience of the hospital discharge pathway more generally. There appear to be some more general and continuing concerns, however, in the area of mental health. This is an area where the interests and wishes of both the patient and the carer may have to be balanced and where expectations may be different.

These issues have been recognised. In August 2009 the Department of Health issued guidance [29] to mental health services on information sharing. This guidance confirms the importance of management and professional leadership. It recognises the role of carers in helping recovery and in their support role.

Where people lack capacity to consent to information sharing, the Mental Capacity Act Code of Practice sets out the legal position. In summary, information may be shared in such circumstances if it is in the best interests of the person who lacks capacity. In practice the carer's own knowledge of the person means they may have some information already.

#### *“ Carers*

*30. Carers have a large part to play in helping recovery and ensuring continued health. To do this, they need access to the right level of information. They frequently report feeling cut off from the care of an individual to whom they have provided considerable support. They may also need information for their own safety.*

*31. They may have information to offer, want advice on how to cope in the future, need help to access different services or simply want to know about progress and the outlook for the future. The advantage of sharing information with carers should be explained to the service user and, even if they are resistant to this when unwell, a further approach should be made when their health improves. However, it should be remembered that, unless there is an overriding reason, the wishes of the service user must be respected.” [29] [Page 8]*

There may also be scope for further information materials to help promote a better understanding of these issues amongst health and social care professionals, patients and carers. This is something that might be explored further, both nationally and locally, in partnership with carer and service user led organisations.

#### **Young Carers**

There is also some evidence from feedback from young carers, including those of parents with mental health needs and/or involved in substance misuse, that their need to understand and to know about concerns and events may not be recognised.

As one young carer has said *“It is the worry of it all”* [30] that impacts most. Appropriate recognition, involvement and sharing of information can make an important contribution in helping to manage concerns without perpetuating the continuation of inappropriate caring roles.

Hospital discharge, where a young carer is involved, is also an area where **“Think Family”** [31] concepts may have a particular contribution to make. It is essential that discharge plans identify and assess needs of parents so they do not have to rely on their children to provide care. It is an issue we hope may be able to be picked up in regional seminars planned for 2010 with special reference to parents with mental health needs or involved in substance misuse. It is also an area relevant to the implementation of the ADCS/ADASS Joint Memorandum of Understanding [51].

#### 4. RECENT EVIDENCE & EXPERIENCE

It is apparent that there is a wealth of policy and practice guidance designed to ensure appropriate and timely discharge from hospital. These materials include guidance on carer involvement. Concerns continue, however, with evidence that:

- some carers do not as yet feel their role and the implications of that role are fully recognised; and,
- the recognition and support given does not reflect their role as carers or treatment as partners in caring; and,
- systematically collected evidence on good outcomes for carers and the person they care for, nationally or locally, is largely absent.

In March 2005, the Health Overview and Scrutiny Committee of East Sussex County Council published a report [32] of a review looking at how carers are recognised, engaged and valued within their local health economy. The review covered three areas, one of which was hospital admission and discharge. The findings drew on a range of sources including research. It is one of a number of scrutiny reviews and illustrates the contribution health scrutiny can make [33] [34].

Within East Sussex a “**Code of Practice for Involving Carers**” was in place. This code set out a number of standards for involvement. Senior nurses identified an ongoing need for reinforcing front line awareness of the code and the potential for different types of admission [e.g. elective and emergency] to impact on its operation.

There was a consensus amongst carers that it was hard to get staff to listen to them. Carers reported a mainly negative view of hospital discharge with specific concerns around timing. They wanted professionals to listen to them in hospital and at “every stage”. The report made a number of recommendations designed to improve carer’s experience of hospitals. They were:

- Carers being given time to arrange for the discharge of the supported person.
- Carers’ needs being taken into account on admission and on discharge of the person they supported who was currently a patient.
- Carers being listened to by health care professionals.
- Carers not being required to continually repeat the same information to staff.
- Training being provided by health care staff for new carers.

Local Involvement Networks [LINKs] are also reviewing how discharge process work. For example, North Tyneside LINK produced a paper [35] [36] in support of an Overview and Scrutiny Exercise looking at patient and carer experiences of hospital discharge processes. A number of helpful case studies are given and provide a focus for organisational feedback and learning. Both positive and negative experiences were identified and the following themes emerged:

- Assumptions made about and lack of family/carer input
- Problems caused by late/delayed discharges [late medication and transport]
- Problems and confusion over follow up and lack of information about this
- Lack of carer input into assessments of the patient’s ability to cope at home and of patients declining assessments and carers not being told about this.

- Poor co-ordination of services, lack of consistency and communication between professionals and from professional to carers and patients and the value of a lead professional to improve communication.

Many of these messages find expression in a much wider literature review by Acton Shapiro in 2007 [37]. This interim report identified issues around discharge felt to be linked to the improved outcomes that are the focus of this paper. They were:

- 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 patient 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 in support of their role;
- the necessity of encouraging better communication across health and social care; and,
- the need for increased awareness of the carer role amongst hospital staff.

The overall message was of a continuing gap between what national policy said should happen and what people experienced. The interim report states that:

*“Even where services and initiatives to support carers through the discharge process exist, there is only limited evidence from evaluation to demonstrate the 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.”*

Research commissioned by the City and Hackney Carers Centre and undertaken by City University, London, with the active support of three local hospitals was reported in April 2007. [38] It made use of a questionnaire based study, and more detailed interviews with carers. Whilst the numbers are small, the study is helpful in that it identified issues and made practice recommendations to respond to them.

The key findings were as follows:

#### **[a] Support during hospital stay**

- Over two thirds had received some information but over half said it was hard to obtain information and carers felt reluctant to bother busy staff.
- Between a half and two thirds of carers felt that hospital staff did not understand their needs; did not treat them as equal partners and felt they were not consulted enough about care and treatment of the patient.
- In the hospital where there was a Carers Support Specialist for certain wards, four out of seven respondents mentioned that person.
- A third expressed concerns around nursing attitudes and communication.

#### **[b] Supporting Carers**

- In the majority of cases discharge planning took place and in the majority of these cases carers said they were consulted; although just over half felt they should have been more involved.
- Whilst over half of carers were clearly dissatisfied with the support they themselves received almost a third rated it as good or very good.
- The major concern was the availability of staff and willingness to engage with carers with allied issues about feeling listened to enough.
- Just under two thirds indicated the hospital hadn't checked with them whether they could cope after discharge; although a quarter felt the hospital had helped them to prepare.

#### **[c] Support through the discharge process**

- Some 60% felt that the patient had been discharged at the right time but a third felt it had been too early.
- Nearly half of carers were not satisfied with the discharge support from the hospital but a third felt it was satisfactory.

#### **[d] Support after Discharge**

- Just less than half received information but around a third felt they would have liked more.
- The majority of respondents [88%] had had some support with most of this coming from statutory and voluntary services
- Just under a quarter said that they or the person they cared for were receiving direct payments.
- Just over half had had a carers' assessment and there was a strong relationship between this aspect and support from Hackney carers' centre.

Communication between professionals and between carers and ward teams appears to be an underpinning issue of concern. It also appears that ward staff had little or no contact after discharge. In the absence of this "feedback loop" staff were largely unaware of how arrangements had gone in practice: they had no opportunity to build this into their practice. There are some interesting parallels with the next study.

The Moffat Project in Scotland [Crisis Prevention for Carers] is a two year pilot project managed by the Princess Royal Trust for Carers. It is aimed at preventing crisis for carers and to reduce waiting times for discharge and risks of emergency readmissions. The initial findings [39] from carer questionnaires and discussions were presented at a conference in 2008.

- 85% of carers were women, 28% cared for their partner, 20% were caring for a disabled child and 25% for a parent or in-law.
- Around half were aged 45-64 and just under a third were over 65. Many had been caring for some time and have experienced negative health impacts.
- Conditions of the cared for person included dementia [16%], heart disease [15%] and stroke [12%].
- On many measures carers reported variable experiences with responses spread evenly from very poor [25%] to excellent [14%] on support received from hospital and social work staff
- Only 29% felt their expertise was recognised by service providers
- Only 27% felt care professions understood their needs as carers
- Around two thirds of respondents were not asked if they were a carer; few received training post discharge or were advised of their right to an assessment.
- A majority of carers did not feel supported as a carer and the needs of many carers appear not to be met
- Carers centre data indicates that for "Moffat" carers 70% were informed of a right to an assessment with 88% identified as carers during hospitalisation and more likely to be involved in the discharge process [30%]:

These research messages also have echoes within the area of mental health. A carers' research group at the Humber Mental Health Teaching NHS trust has been in place since 2003. It has developed a questionnaire which measured carers' satisfaction with the service on offer. In August 2008 the Trust Board considered a report [40] arising from the research. It identified a number of barriers to collaborative working. They were:

- Documentation that did not support easy identification of people who wished to be involved in supporting the service user in a journey to recovery.
- Carers seen as primarily in need of support themselves rather than as partners in the task of enabling the service user.
- The perception of service user confidentiality as a barrier to engaging with carers and a lack of skills sharing on ways of working through this.
- The absence of guidelines and a systematic approach to communication with carers.
- A culture which focussed on an individual approach to carers and did not emphasise the importance of communicating with and working with families.
- Resource pressures that made innovations in practice difficult either to implement or to sustain.

In summary, these messages point to quite variable experiences and highlight:

- a continuing gap between policy, practice and the experience of a number of carers and patients;

- designated carer support staff within acute settings may improve recognition, take up of assessments and improve overall experiences within discharge processes;
- a leadership requirement to work on and challenge the sometimes adverse impacts of attitudes towards and assumptions about caring roles on the effectiveness of discharge processes;
- the benefits and vital contribution accessible and appropriate information and opportunities for direct support can make;
- the need for more evidence and feedback to help assure quality experiences for carers and patients and promote learning across the care pathway;
- the potential for capacity, resource and service pressures to adversely affect ability to sustain good practice within the complete care pathway.

Overall the findings of recent research [41] and the key messages arising from the studies outlined above indicate:

- a continuing need to focus on the impacts on and outcomes for carers and the person cared for arising from their experience of the hospital discharge process and afterwards; and,
- a real need to change attitudes and cultures if improvements in experience and outcomes for carers are to be achieved.

## 5. DEMENTIA, CARERS & HOSPITAL DISCHARGE

Prevalence of dementia rises rapidly with advanced age. Adults over 85 are significant users of acute hospital inpatient provision. Up to 70% of hospital beds are occupied by older people and up to half of these may have cognitive impairments. **“Living well with Dementia: A National Dementia Strategy”** [10] is an important step forward in improved recognition, support and quality care for people with dementia in England. It links with the principles in **“Putting People First”** [42].

The strategy has 17 key objectives. Of these, four have a special relevance in the context of hospital discharge support:

- Good quality information for those with diagnosed dementia and their carers
- Implementing the Carers Strategy
- Improved quality of care for people with dementia in hospitals
- Improved intermediate care for people with dementia

Those with dementia and those who care for them may face particular challenges arising from hospital admission, stays and discharges. The national strategy recognises the need to strengthen ownership and leadership on dementia in general hospitals. It recognises the challenges busy wards can present to people who have or may have dementia and who are also unwell. It notes that:

*“often insufficient information is sought from families and carers... Currently families are often excluded from discharge planning so false assumptions are made about whether it is possible for people with dementia to be cared for at home.” 51/52*

The national strategy proposes that:

*“the care pathway for better management of people with dementia, including pathways out of hospital, should be developed in consultation with local social services and user and carer organisations.”*

The role of specialist liaison teams is already recognised within clinical guidelines [43] and a range of approaches have been adopted. The national Implementation plan, whilst it looks at improved quality of care in hospitals and in intermediate care, does not appear to consider the scope for specific further work on the hospital discharge pathway within acute and specialist settings as a means of securing improved outcomes.

The potential value of considering the whole pathway, the experience of patients and carers within it and the role of specialist support, may be seen in Sheffield. Here the Council and Sheffield Health and Social Care Foundation Trust have come together to develop an Accelerated Discharge Dementia Team [ADDT] [44]. This team provides specialist support to people with dementia, or who may have dementia, enabling them to leave hospital and return home.

The service aims to reduce risks within the discharge pathway and to provide information, support and advice to patients carers and hospital staff caring for people with dementia. Key aspects of the scheme are:

- Multi disciplinary assessment of the home, current needs, cognitive functioning and mental health
- Allocation of a support worker who will make contact on the ward and visit at home for up to two weeks after discharge.
- Provision of support to help adjustment at home
- Trial discharges at home

The team aims to support the ward in discharging the care of patients with dementia and not to take over their care within the accepted hospital discharge pathway. The aim is to troubleshoot any difficulties in the immediate post discharge period and so reduce risk of delayed discharge or readmission.

How discharges are planned and take place is as important as what happens in terms of maintaining a sense of being valued as people and as partners in caring. As a recent report by the Nuffield Council on Bioethics [45] states;

*“... we highlight the enormous importance of families and friends in the care of many people with dementia. It is our view that an attitude of working with families and other carers, supporting them in their own care of the person with dementia is most conducive to the interests of the person with dementia ... We suggest the appropriate attitude of professionals and care workers towards families should be that of **partners in care**... Such partnership would involve a relationship of trust between professionals and carers, based on mutual respect for each other’s role and expertise. Page xix [emphasis added]*

The need for and value of systems wide partnership working is identified as a key message in a recent Research in Practice Paper [46] It states:

*“There is a need to develop comprehensive local services that work in partnership both with the person with dementia, their primary carer and their wider support network. Carer support should be available across the entire “care-giving career” and not limited to the time when carers are providing “in home” care.*

These messages are entirely consistent with the view that hospital discharge is part of a wider and longer care pathway and has specific competences within it [47]. The issues around dementia, partnership and discharge reflect the message by Lord Darzi contained in the Foreword to this paper and the need to secure cultural and attitudinal shifts across all sectors and an ability to work in ways that recognise:

*“ People live out their lives in their own homes and communities. It is here that their health and well being is shaped by the circumstances in which they find themselves.”*

## 6. EXPLORING THE ISSUES – WORKSHOP SUMMARY

In September 2009 ADASS arranged a day workshop on carers and hospital discharge to explore these issues further. The workshop had the following overall aim for participants:

*“To consider recent evidence, share their own experiences and through discussion to identify ways in which we can work together better to improve carer recognition, support, experiences and outcomes whilst sustaining person centred, timely and supported hospital discharge for all patients and to reduce risks of early breakdown or hospital re-admission”.*

The workshop was made up of carer organisations, health and social care professionals. It consisted of a series of short presentations, group and individual discussions and a plenary review. The main points and summary of themes emerging from the day were:

Carers were felt to be helped within hospital discharge processes by:

- Information/dedicated workers with a carers brief
- Identification and recognition of their role as carers
- Treating carers as partners and involving them
- Joined up working, follow up and use of feedback

Areas seen as unhelpful to carers within hospital discharge processes were:

- Some professional/ward attitudes and cultures [internal hospital factors]
- Assumptions made by professionals about caring and carer capacity
- Systems and documentation that did not fully recognise carers
- Lack of information or restricted ability to engage on both sides

Having identified these themes, the workshop considered ways to make a difference for carers and the benefits that might flow from improving hospital discharge processes. Lord Darzi’s four ambitions for the transformation of community services [2] were used as a framework for this:

- Getting the basics right – every time
- Making everywhere as good as the best – high impact changes
- Delivering evidence based practice
- Developing and supporting people to design, deliver and lead high quality community services

These ambitions were looked at in terms of:

- Making a difference for *people who were already carers* at the time of admission of the person they supported.
- Making a difference for *people who will become carers* on hospital discharge.
- Making a difference for *specific groups of carers*: young carers and adult carers of people with mental health needs, or involved in substance misuse, or people with dementia]

The main themes emerging from discussion were:

- **Getting the basics right – every time**
  - Understand and use the current guidance
  - Focus on families whilst maintaining patient focus
  - Adopt pathway models and whole systems approaches
- **Making everywhere as good as the best – high impact changes**
  - Improve leadership and partnership working
  - Ask the right questions at the right time of carers
  - Develop assurance mechanisms around transitions and care pathways
- **Delivering evidence based practice**
  - Improve and use feedback data around transitions and care pathways
  - Use opportunities for more information collection from carers/patients
  - Develop follow-up and systematic analysis; including, readmission data
- **Developing and supporting people to design, deliver and lead high quality community services**
  - Promote leadership around what makes a difference
  - Try to put yourself into the carer's shoes [impacts]
  - Grow staff understanding and ownership of the benefits within the care pathway as a whole and promote cultural change

The final workshop session generated some initial “headline” thoughts around possible “next steps”. In terms of moving the agenda forward, a number of pointers were noted around the need to:

- have robust policy and practice guidance;
- ensure the same messages are given from all sources;
- Build understanding of cost effectiveness and the value of the carer contribution;
- get more of a steer into operating framework [Level 1 – 2];
- engage key players [e.g., Deputy Chief Nurses] in acute settings;
- ensure recording/ documentation is filled in and includes carer and patient experience; and,
- make use of regulatory processes to help assure policies/processes.

The workshop concluded with a review of the day. The following points were made.

- Recognise hospital discharge occurs within a longer care pathway.
- Generate evidence to support what works, what does not and what delivers the most effective overall outcomes.

- Re-emphasise nature of hospital discharge as a multi disciplinary process and that this includes responsibility for eventual and overall outcomes across the care pathway [outcome based accountability].
- Offer accountability and leadership to:
  - encourage improvement; and,
  - recognise shared accountability across the pathway.
- Consider the role of inspection and regulation in terms of assurance around discharge processes and experiences and promotion of learning.
- Explore potential for “on line” customer services, information and feedback that is shared and used to improve quality.
- Ask ourselves and others how can we make a difference:
  - through workforce development
  - better information [NHS choices, Carer Direct]
  - more sophisticated indicators of quality and performance
- Engage LINks and Council Overview and Scrutiny functions to:
  - ask the right questions; and
  - gain views on how things are for carers in terms of national and local strategic outcome
- Empower people to ask the right questions and feel confident in doing so.
- Keep in mind issues around the end of the caring role in the context of end of life support/systems within the community.

There is a fairly strong “read across” with the difficulties identified in current practice guidance. This suggests that some of the challenges may be fairly enduring in nature. In the present difficult economic climate and restraint of public expenditure, the pressures on capacity and resources are likely to grow. Improving quality in terms of both process and outcomes, however, offers benefits in this context. As Lord Darzi has indicated:

*“...quality is fundamentally linked to efficiency – doing things right the first time, so they don’t have to be done again. This not only makes sense in terms of efficiency, but also patients’ experience of the care they receive. That is why quality and productivity must go forward together.”*

One area we identified, where there is relatively little evidence and where much more information would be valuable, is the experience of carers from black and minority ethnic groups (BME) within hospital discharge processes. Whilst there is material relating to the area of mental health [48], evidence of how discharges from acute hospitals impact on BME carers appears to be very sparse.

We need to pick up this challenge. The rights based approach inherent in the Equalities Bill points to a need to tackle language, cultural and other barriers that may limit access to information and involvement. [49] Just as assumptions are made about carers generally there may also be assumptions about caring capacity by particular black and minority ethnic groups. These can make the task of caring on discharge more lonely and demanding than it might be otherwise. [50]

In terms of young carers, we need to ensure that discharge plans fully recognise and meet the needs of patients who are parents of children under 18 so that they do not have to rely on their children to provide care as outlined earlier in this review.

## 7. THEMES FOR IMPROVEMENT

The first and most important point to note is that the majority of hospital discharges are timely, safe, relatively straightforward and satisfactory in terms of experience and outcomes for patients and, where involved, their carers. There do appear to be real and continuing issues, however, around the quality of some simple and complex hospital discharges. Carers continue to report negative experiences both in terms of the discharge process itself and what happens afterwards. There are a number of themes for improvement that have emerged. They are:

- [a] There is a body of policy and practice advice which if applied consistently at the front line and owned at senior/board level should ensure recognition and involvement of carers as partners in discharge processes. The evidence and experience available, whilst limited, suggests this does not always happen.
- [b] Opportunities to learn from experience of discharge processes and feedback on eventual health and support outcomes appear limited. The result is that acute settings are generally unaware of “what happened next”. This means they do not have the opportunity to review practice and to ensure more consistent and better outcomes within timely and safe discharge processes for carers and patients. This may have special relevance to BME carers.
- [c] There appears to be a negative and potentially self reinforcing circle, with its origins in perceptions and assumptions about capacity and opportunities to work as partners in caring, that prevents engagement by both professionals and carers alike in ways that are not helpful to either party.
- [d] The presence or absence of dedicated workers for carers or community support services for carers appears to have an impact on carer experience around carrying out of assessments and the ability to exercise rights within discharge processes. This may have a special relevance to BME carers.
- [e] Leadership on partnership working across health and social care is essential if systems are to work in ways that carers and patients find helpful and in support of using Local Area Agreements to strengthen commissioning.
- [f] There appears to be scope to strengthen assurance mechanisms around discharge processes and, given the involvement of both health and social care systems, real value in a thematic review by the Care Quality Commission to identify what works and what might work better.
- [g] There is a good case for improving research evidence in this area since it would provide a stronger basis for driving up quality of experience and better overall outcomes in line with Darzi principles.
- [h] There is potential for LINKs and Council Overview and Scrutiny work to gain momentum on these issues and to improve outcomes for carers and patients.
- [i] There is value in using the ADCS/ ADASS outcomes for young carers [51] to inform hospital discharge processes and in ensuring parents do not have to rely on children to provide care to make a hospital discharge plan work.

## 8. NEXT STEPS

The themes for improvement point to a need for action. Some of the issues are not new but the fact that this is so should encourage us to ask how we can get closer to the quality of experience for carers and patients and outcomes we all want to see.

Delivering improved partnership around improved timely, safe and positive patient and carer outcomes is the underlying driver for what we are putting forward. We believe the climate is right to make a real difference and promote a transformational shift in the way hospital discharges are planned and happen. We intend to:

- Supply a copy of this review to every Director and Lead Member for Adult Social Services, Chief Executives of Primary Care Trusts and Chief Executives of all Acute and specialist Mental Health NHS Trusts.
- Make this review available to national carers' and related organisations to encourage dissemination of its key messages so that carers can test the findings in context of their own experience and shape further discussion.
- Encourage Directors and their local strategic partnerships to consult with carers and their representatives, as part of their wider health and well being work, or as part of an Overview & Scrutiny or LINKs programme, on how well local hospital discharge processes are working generally and the scope for using outcome based accountability frameworks.
- Invite the Chief Executive of the NHS and the Director General, Social Care Local Government and Care Partnerships, to encourage joint local action to improve feedback and quality assurance around hospital discharge experiences, impacts and outcomes for carers and patients.
- Encourage the Care Quality Commission to undertake a thematic review at an early date of the hospital discharge care pathway and how it works; including, areas for shared learning and outcome improvement.
- Share this paper with the Standing Commission on Carers as part of our commitment to the implementation of the national strategy and to encourage opportunities for further debate and dissemination around what it contains.
- Emphasise the value of research and systematic feedback from carers and staff to promote learning around safe, sound and supportive hospital discharge practice locally and nationally and the need for more information about the experiences of BME carers.
- Review progress and develop our thinking by further discussion through the ADASS Carers Reference Group and, for example, inclusion of these review findings as a topic area within the next ADASS Spring Seminar.
- Encourage consideration of issues impacting upon young carers within hospital discharge processes as part of the local arrangements for taking forward the ADCS/ADASS Joint Memorandum of Understanding. [51]

## **APPENDICES**

## APPENDIX A

### HOSPITAL DISCHARGE

- Understand your local community and balance the range of service to meet health, housing and social care needs
- Ensure individuals and their carers are actively engaged in the planning and delivery of their care.
- Recognise the important role carers play and their own right for assessment and support.
- Ensure effective communication between primary, secondary and social care to ensure that prior to admission and on admission each individual receives the care and treatment they need.
- Agree, operate and performance manage a joint discharge policy that facilitates effective multidisciplinary working at ward level and between organisations.
- On admission, identify those individuals who may have additional health, social and/or housing needs to be met before they can leave hospital and target them for extra support.
- At ward level, identify and train individuals who can take on the role of care co-ordination in support of the multidisciplinary team and individual patients and their carers.
- Consider how an integrated discharge planning team can be developed to provide specialist discharge planning support to the patient and multidisciplinary team.
- Ensure all patients are assessed for a period of rehabilitation before any permanent decisions on care options are made.
- Ensure that the funding decisions on NHS continuing care and care home placement are made in a way that does not delay someone's discharge.

**Source:** *Foreword, Discharge from hospital: pathway, process and practice, Department of Health, 28 January 2003, Pages v -vi*

## APPENDIX B

### KEY PRINCIPLES OF EFFECTIVE DISCHARGE AND TRANSFER OF CARE

- Unnecessary admissions are avoided and effective discharge is facilitated by a “whole system approach” to assessment processes and the commissioning and delivery of services;
- The engagement and active participation of individuals and carers[s] as equal partners is central to the delivery of care and the planning of a successful discharge;
- Discharge is a process and not an isolated event. It has to be planned for at the earliest opportunity across the primary, hospital and social care services, ensuring that individuals and their carer[s] understand and are able to contribute to care planning decisions as appropriate;
- The process of discharge planning should be co-ordinated by a named person who has responsibility for co-ordinating all stages of the “patient journey”. This involves liaison with the pre-admission case co-ordinator in the community at the earliest opportunity and the transfer of those responsibilities on discharge;
- Staff should work within a framework of integrated multidisciplinary and multi-agency team working to manage all aspects of the discharge;
- Effective use is made of transitional and intermediate care services, so that existing acute hospital capacity is used appropriately and individuals achieve their optimal outcome;
- the assessment for, and delivery of, continuing health and social care is organised so that individuals understand the continuum of health and social care services, their rights and receive advice and information to enable them to make informed decisions about their future care.

**Source:** *Discharge from hospital: pathway, process and practice, Department of Health, 28 January 2003 [Page 3]*

## APPENDIX C

### HOSPITAL DISCHARGE

#### PATIENT'S AND CARER'S DISCHARGE STANDARDS [For inclusion in Patient & Carer leaflet]

Patients being discharged from hospital have the right:

1. To full information on their diagnosis and the assessment of their health and social needs in preparation for discharge.
2. To be fully involved in planning their own discharge, together with a relative, carer or friend as appropriate.
3. For the discharge plan to start on or before admission where possible.
4. To full information on the services available in the community relevant to their care.
5. To full information on short or long term nursing or residential care; including financial implications.
6. To be given an appropriate contact number where they can get help or advice on discharge.
7. To be given a clear, legible discharge letter detailing the support services provided for them [where appropriate].
8. To full information on health authority eligibility criteria for continuing care.
9. The discharge planning team to be available as a point of contact to offer support and advice to patients, carers, statutory and voluntary agencies.
10. Information on advocacy support.
11. To have access to the trust complaints procedure and any complaint regarding their discharge arrangements investigated and a full explanation given.
12. If still not satisfied, then to be given access to the health service commissioner

**Source:** *Discharge from hospital: pathway, process and practice, Appendix 4.3, Department of Health, 28 January 2003.[Page 45]*

Note: adapted from the work of the liaison nurses, York Health Services Trust.

## Carers and hospital discharge - a good practice checklist

### Choice

Allow carers time to make choices about

- taking on the role of carer
- whether to continue caring
- how much and what type of care, taking into consideration family and caring commitments, work, education, social activities.

### Identification

- Throughout the hospital discharge process and at the earliest opportunity, ensure there are triggers in place to identify carers.
- Be aware that carers may not view themselves as carers but as partners, parents, sons, daughters, etc.

### Information

- Actively seek permission from patient to share information with the carer.
- Provide carers with information about
  - discharge plan in writing and verbally
  - medical condition of patient
  - carer's right to an assessment
  - what is likely to be involved in caring
  - benefits
  - financial implications of caring
  - charging for services
  - other sources of help and support organisations, such as carers organisations and self help groups
- access to signers/interpreters to enable effective understanding and communication
- challenging decisions and complaints procedures

### Assessment

- Inform carers about their right to an assessment and ensure carers are given information about how it may benefit them.
- Involve carers in assessments, including those carried out by occupational therapists, physiotherapists, community nurses etc.

### Planning for discharge

- Ensure carers feel fully involved at all stages of discharge including the decision to discharge the person and making sure practical arrangements are in place
- View carers as partners, respect and listen to their views - longer term carers are likely to have considerable expertise and skill of how to care for the patient
- Acknowledge carers' individual needs, consider cultural differences, age, race, disability, religious background, sexual orientation, gender assumptions, geography
- Ensure carers have been involved in drawing up, monitoring and reviewing policy and its implementation
- Develop different types of consultation procedures such as those discussed in "Involving and Consulting Carers" (available from [www.carersonline.org.uk](http://www.carersonline.org.uk))

### Support

- Be flexible: provide services that carers want, when they want them
- Ensure practical help is in place prior to discharge
- After discharge, check to find out if care package is actually supporting the carer
- Offer training on how to care safely; e.g. administering medicines, dealing with difficult behaviour, lifting and handling
- Improve co-ordination between Health and Social Services to ensure carers receive a seamless service

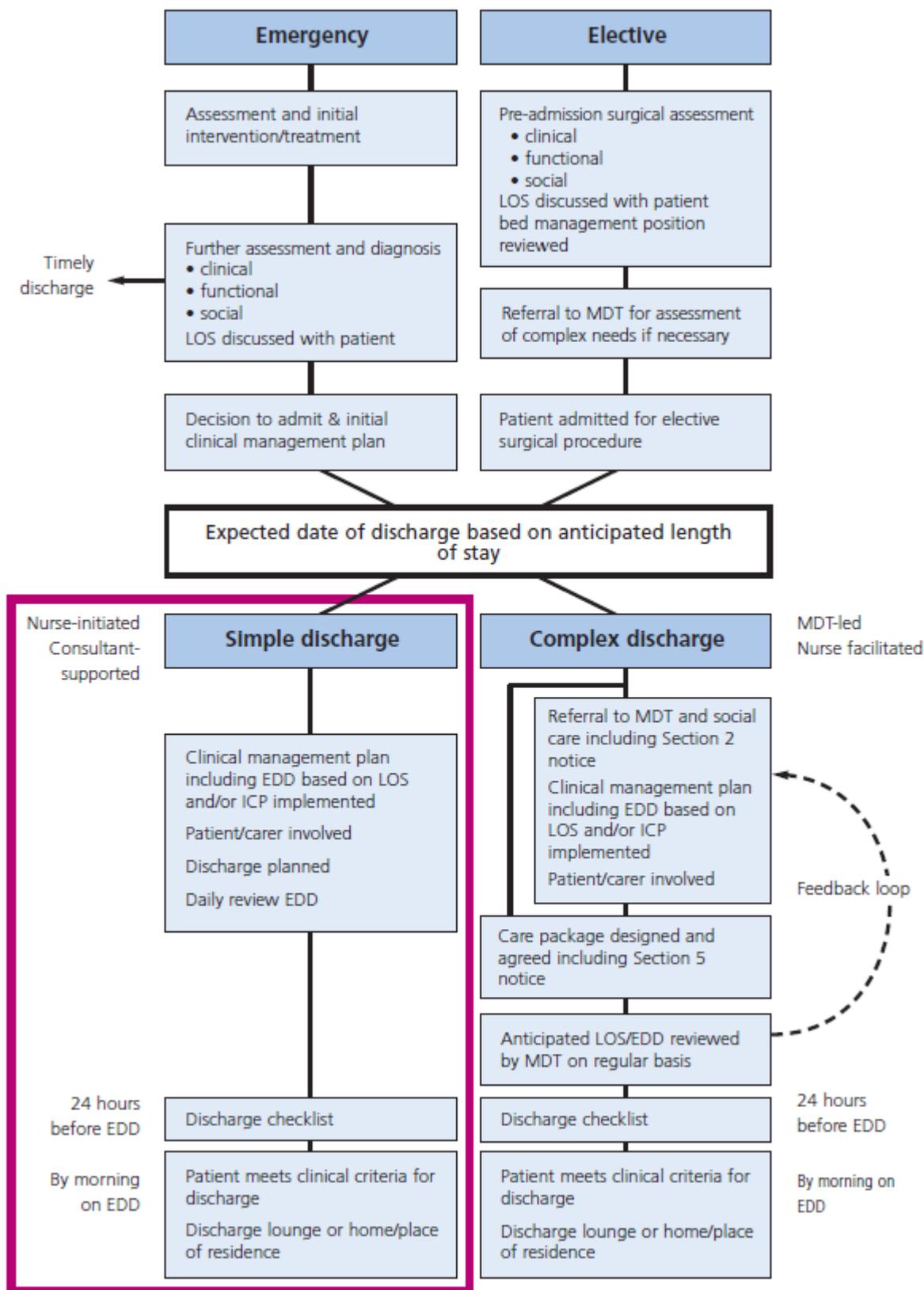
### Monitoring

- Find out whether carers' outcomes were met by the hospital discharge process. Methods of carrying this out include:
  - Patient / Carer satisfaction surveys
  - Audits of discharge documentation provided to carers
  - Measure number of carers assessments
  - Review policies regularly in consultation with carers organisations

Source: *Carers Checklist, 2003, Carers UK, [11]*

**APPENDIX E**

**HOSPITAL DISCHARGE FLOW CHART  
[SIMPLE AND COMPLEX DISCHARGES]**



*Achieving timely 'simple' discharge from hospital: A toolkit for the multi-disciplinary team* 13

**Source: Achieving timely “simple” discharge from hospital, Dept. of Health, August 2004 [5]**

## APPENDIX F

### COMMISSIONING CARE PATHWAYS

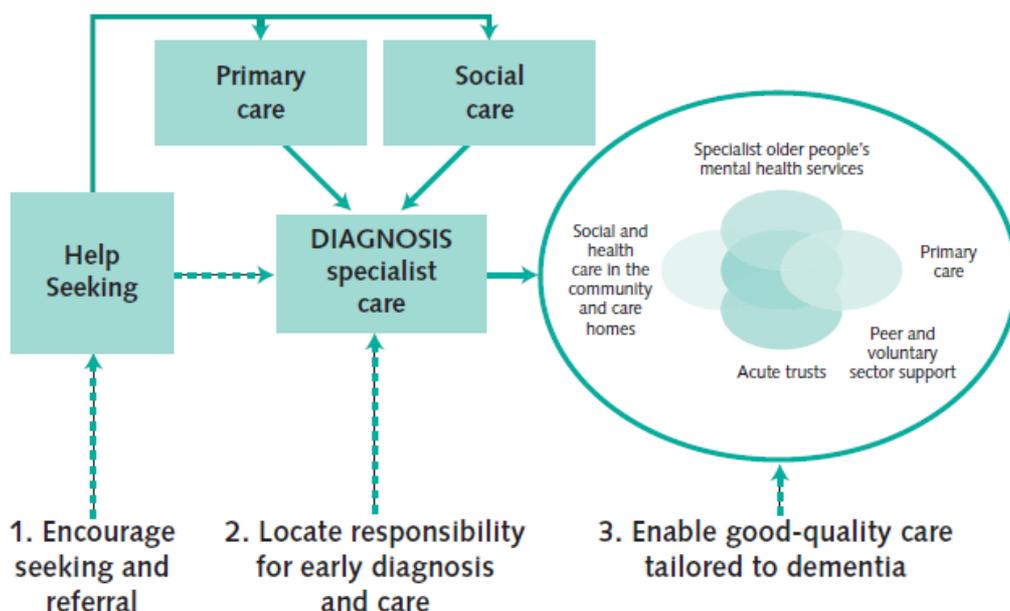
#### 4. Commissioning a care pathway for people with dementia and their family carers

The Department of Health’s goal is for people with dementia and their family carers to be helped to live well with dementia, no matter what the stage of their illness or where they are in the health and social care system. The vision to achieve this is a simple one, in three parts, to:

- encourage help-seeking and help-offering (referral for diagnosis) by changing public and professional attitudes, understanding and behaviour;
- make early diagnosis and treatment the rule rather than the exception. This will be achieved by locating the responsibility for the diagnosis of mild and moderate dementia in a specifically commissioned part of the system that can a) make the diagnoses well, b) breaks those diagnoses sensitively and well to those affected, and c) provides individuals with immediate treatment, care and peer and professional support as needed; and
- enable people with dementia and their carers to live well with dementia by the provision of good-quality of care for all with dementia from diagnosis to the end of life, in the community, in hospitals and in care homes.

The care pathway set out below (Figure 1) illustrates a coherent system for the basis of local commissioning.

Figure 1: Care pathway summarising the three themes of the National Dementia Strategy and the commissioning challenges



Source: *Living well with dementia: A national Dementia Strategy* p.90

## APPENDIX G

### BENEFITS OF IMPROVED DISCHARGE PROCESSES

#### Factsheet 3

#### Benefits of improving discharge processes

Improving discharge processes has distinct benefits for patients, the service and for health professionals. Use these points to make the case to stakeholders about the benefits to be gained from improving the discharge process.

##### *Benefits for patients*

- Identifying expected date of discharge can help patients to plan for when they go home
- Patients' own responsibility for elements such as transport and arrangements at home can be clarified, discussed, and agreed in advance
- Patients' experiences can be improved when they have more information about their care and they feel included in the decisions
- Patients have more realistic expectations of the care they will receive
- Patients only stay in hospital for the optimum amount of time for their recovery and are less likely to pick up hospital acquired infection

##### *Benefits for the service*

- Health and social care can work as a whole system, supported by a managed care approach, resulting in improved quality, better match between demand and capacity, and better use of resources such as staffed hospital beds
- Improved discharge processes contribute to improving patient flow and the effectiveness and efficiency of the system: right patient, right place, right time
- Increased bed days will be available for the organisation, reducing queues and cancellations
- More effective communication between hospital and community will mean more streamlined services for all
- Consistency in approach to single assessment and services based on need – joint assessment processes mean an integrated approach and less time wasted on duplicating the assessment process by different teams

##### *Benefits for health professionals*

- Improved discharge processes make professionals' working lives easier and clearer
- seeing their role as part of the whole system with each part impacting on the effectiveness of every other part
- The development of proactive processes and taking a more managed care approach to their work, leading to greater job satisfaction
- Professionals have an increased sense of responsibility, recognition and support for the work they contribute
- Clinical team members will be directly contributing to improving the patient's experience of healthcare

[Source: Achieving timely "simple" hospital discharge: a toolkit p. 37] Dept. Health 2004 [5]

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## NOTES

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