

HOSPITAL DISCHARGE: THE CARER'S JOURNEY

**Training pack developed on behalf of Action for Carers
(Surrey) and Surrey County Council by:**

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Introduction to the pack

The purpose of this pack is to provide a training tool on the key elements of involving Carers in the process of hospital discharge.

The materials can be used flexibly to meet the differing learning needs of both professionals and Carers involved in the hospital discharge process. They should be used in conjunction with the Department of Health guidance, “Discharge from hospital: pathway, process and practice.”

Learning outcomes

Participants involved in the training will:

- ◆ Have a greater understanding of carers’ experiences during hospital discharge
- ◆ Increase their knowledge of Carers rights in relation to hospital discharge
- ◆ Explore the benefits of involving Carers as equal partners during the process of hospital discharge
- ◆ Identify ways to:
 - a. involve Carers in the process
 - b. enable Carers to make informed choices
- ◆ Consider different types of information and support that will assist Carers through the hospital discharge process

Sections in the pack

- ◆ Introduction and policy context
- ◆ Pathway and process of hospital discharge
- ◆ Involving carers and enabling choice
- ◆ Information and support for carers

Methods

- ◆ Reading materials
- ◆ Group activities
- ◆ Plenary discussion
- ◆ Presentations
- ◆ Carer/trainer facilitation
- ◆ Audio recording

SUGGESTED PROGRAMME

- 9.30 am **Introduction to the workshop**
- housekeeping
 - aims and outcomes of workshop
 - introducing ourselves
- 9.45 am **The Carer's Journey**
- groupwork (Activity One)
 - hearing from Carers
- 10.30 am **Policy context**
- groupwork using case study (Activity Two)
- 11.00 am *Coffee*
- 11.15 am **Feedback** from case study
- 11.45 am **Benefits of involving Carers**
- groupwork (Activity Three)
- 12.30 pm *Lunch*
- 1.15 pm **Enabling involvement and choice**
- groupwork (Activity Four)
 - good practice checklist
- 2.30 pm **Information and support for Carers**
- groupwork (Activity Five)
- 3.00 pm **Action planning**
- groupwork (Activity Six)
 - feedback
- 3.45 pm **Summary and evaluation**
- 4.00 pm *Close*

Notes for trainer/facilitator

Detailed below are the resources you will need to efficiently and effectively involve participants in the sessions:

- ◆ Comfortable environment with no distractions
- ◆ Flipchart and pens
- ◆ Overhead projector or power point
- ◆ All activities should end with the suggested summary
- ◆ Department of Health Guidance “Discharge from hospital: pathway, process and practice”.

The sessions do not have to be worked through in the order given and not all sessions need to be covered with all participants; some may have identified areas they wish to focus on. There may be substantial understanding already or knowledge which has been demonstrated elsewhere. The trainer/facilitator should establish the individual and group needs before deciding on whether to use all or some of the sessions. Where all sessions need to be covered during the course of one day the suggested one-day programme can be followed.

Certain sessions could be facilitated with a Carer who has been through the experience of hospital discharge, and in particular session one, three and four. You will need to give adequate time to preparing the Carer, so that they feel able to provide a helpful and non-confrontational approach to the training, yet still convey key concerns and issues expressed by Carers. As an alternative edited interviews by Care Radio can be used.

Session One – Experiences of Carers

- ◆ At least 45 minutes
- ◆ Activity Sheet One
- ◆ Summary Sheet – Activity One
- ◆ Overheads numbers.....
- ◆ Flipchart

Session Two – Policy Context

- ◆ At least one hour
- ◆ Activity Sheet Two
- ◆ Summary Sheet – Activity Two

◆ Overhead numbers.....

Session Three – Benefits of involving Carers

- ◆ At least 45 minutes
- ◆ Activity Sheet Three
- ◆ Summary Sheet – Activity Three
- ◆ Overhead numbers.....

Session Four – Enabling Carer involvement and choice

- ◆ At least one hour 15 minutes
- ◆ Activity Sheet Four
- ◆ Summary Sheet – Activity Four
- ◆ Overhead numbers

Session Five – Information and support for carers

- ◆ At least 30 minutes
- ◆ Activity Sheet Five
- ◆ Summary Sheet – Activity Five
- ◆ Overhead numbers
- ◆ Flipchart

Session Six – Action Planning

- ◆ At least 45 minutes
- ◆ Activity Sheet Six
- ◆ Overhead numbers
- ◆ Flipchart

Session Seven – overall summary

- ◆ At least 15 minutes
- ◆ Flipchart
- ◆ Overall Summary Sheet
- ◆ Overhead numbers.....
- ◆ Evaluation form

Session One – facilitator notes

Introducing session one:

A key principle underpinning effective discharge and transfer of care is that discharge has to be seen as a process and not an isolated event. It has to be planned for at the earliest stage possible, either prior to admission if elective surgery or in A & E if an emergency.

The new guidance talks about this process as the ‘patient journey’ and that this journey must be co-ordinated by a named person referred to as a care co-ordinator. Show OVERHEAD ONE to illustrate the different stages of that journey. Draw attention to page 56 of the guidance which gives a more detailed hospital discharge pathway.

Carrying out activity one:

This first activity is designed to get participants thinking about the ‘carer journey’ and what it might feel like at a particular stage during that journey.

Participants to complete Activity Sheet One in small mixed groups. It is important that participants think about how THEY may feel if faced with the scenario presented.

Take feedback, jotting down key points onto flipchart under the three questions headings of Feelings, Concerns and Help.

Carer Trainer to talk about their experiences at other stages of ‘The Carers Journey’. If a Carer Trainer is unavailable, the Care Radio recording can be used.

Summarise statistics from research using OVERHEAD TWO and give out summary sheet one.

ACTIVITY ONE – THE CARER’S JOURNEY

This first activity looks at what it might feel like to be a Carer at a particular stage during the hospital discharge process. Work in small groups and place yourself into the following scenario:

A close relative or friend has just had a serious fall at home. You accompany him/her to A & E where it is confirmed that the hip is broken and that they will need to be admitted onto the ward for treatment and a period of rehabilitation before being discharged home again.

How might you be feeling at this time?

What might be your worries or concerns?

What might help you at this time?

Summary Sheet 1

Experiences of Carers

Research has shown that when a person is admitted to hospital, the point at which they are discharged is crucial to the Carer. The amount of information shared with the carer, the degree of choice about taking on caring responsibilities, the level of planning and services all directly affect the carer's health, well-being, income, ability to care and quality of life.

In Carers UK research, *Caring on the Breadline*, published in June 2000, showed that six out of ten carers had had to give up work to care. This combined with high disability costs and low benefits causing lasting poverty amongst carers. Six out of ten carers believed the constant worry about money was affecting their health leading to two patients not one.

“You can take him home now”, 2001

This Carers UK study revisits an earlier piece of research *Ignored and Invisible*, carried out by Melanie Henwood for Carers National Association (as then called) in 1998. The purpose of the more recent study was to:

- ◆ Examine whether good practice is being followed in terms of informing, supporting and valuing carers at the point of hospital discharge
- ◆ Examine whether carers experiences of hospital discharge have changed since 1998
- ◆ Seek Carers views about what needs to change in order to improve their experience
- ◆ Inform the implementation of policy and practice under the action plans for the NHS and Social Care

Carers were asked to write about their experiences of hospital discharge, both positive and negative. Many paid tribute to staff and were positive about the way they had been treated. Other were more negative. 28% reported positive experiences, 72% reported poor experiences. Other statistics include:

- ◆ 70% of carers said they had no choice about taking on the caring role when the person they cared for was discharged
- ◆ 71% said they were not told about other alternatives to caring at home, such as residential or sheltered housing (similar to 1998 report)
- ◆ The number of carers who said they had been consulted about hospital discharge plans has fallen since 1998 from 71% to 64%.
- ◆ Correspondingly the number of carers who said they were consulted has increased from 36% in 1998 to 45% in this study.
- ◆ Only 20% of carers said they had received a copy of the discharge plan compared to 28% in 1998.
- ◆ Only half of carers were told about the sorts of care that would be needed after leaving hospital, which is no change since 1998.
- ◆ There has been a rise in the proportion of home visits from 21% to 33%.
- ◆ 27% of people being cared for had to go back into hospital within two months of being discharged compared to 25% in 1998. Carers felt this was because the person had been discharged too early.

Good practice versus bad practice

GOOD EXPERIENCES:

“The experience was brilliant. I attended a meeting of nurses, O.Ts and social services at the hospital where a care plan for my wife’s return was agreed, plus home visits. She was not discharged until the care plan was in place.”

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

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

BAD EXPERIENCES:

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

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

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

“Arrived at hospital at 3.00 pm to be told husband could go home. No transport offered, no home assessment, no advice on caring for him at home. 6pm waiting in draughty doorway in dressing gown for taxi. 6.30 pm he almost collapsed on the driveway.”

“I had no contact with social services following the discharge of my husband from hospital. Apparently we ‘fell through the net’. What little services we have we have had to fight for.”

Session Two – facilitator notes

Introducing session two:

There are a significant number of pieces of legislation, policy and guidance which relate to hospital discharge and Carers. Show OVERHEAD THREE to demonstrate this. Draw attention to the detailed information on each of these pieces within the new guidance, pages 7-13.

It is not possible to go into detail on every single piece of legislation, policy and guidance, however it is helpful to highlight the key messages that run through much of them. Show OVERHEAD FOUR.

Carrying out activity two:

This second activity is designed to familiarise participants with carer's rights during the hospital discharge process.

Participants should complete Activity Sheet Two in small mixed groups. The group should pool their existing knowledge of relevant legislation, policy and guidance as well as use pages 7-13 in the new guidance and summary sheet 2 as reference tools.

Take feedback from groups, jotting down key points onto flipchart.

Identify gaps/summarise using following case study feedback notes

Finish with OVERHEADS 5 summarising key messages within new government guidance and Community Care (Delayed Discharges etc) Act 2003.

An additional handout “Carers and Hospital Discharge – What to Expect” may provide a useful handout for professionals to give to Carers.

Case Study feedback

- ◆ Disabled Persons Act 1986 – Joyce’s and Clare’s needs to be considered
- ◆ NHS and Community Care Act 1990 – Edward “appears to be in need” under section 47, therefore entitled to community care assessment which should involve Joyce and Clare as part of holistic approach
- ◆ Direction on Choice 1992 – Edward and Joyce’s preferred choice on residential accommodation to be taken into account if appropriate
- ◆ Carers (Recognition & Services) Act 1995 – duty on social services to assess Joyce’s and Clare’s needs as providing substantial and regular care. Must be informed of right to Carer’s assessment
- ◆ Modernising Social Services 1998 - Carers Grant may enable provision of breaks for Joyce.
- ◆ Better Care Higher Standards – user friendly copy to be provided to Edward, Joyce and Clare providing information on service standards and provision across health and social care
- ◆ NHS Plan 2000 – PALs may enable Edward and Joyce to express own views. Requires Edward and his family to receive individual care plan
- ◆ Carers and Disabled Children’s Act 2000 – strengthens Joyce’s and Clare’s rights to own assessment. Possible for them to access own services arranged and provided by social services or to receive vouchers or direct payments.
- ◆ Free Nursing Care in Nursing Homes 2001 – if Edward is discharged to a Nursing Home, he is entitled to have nursing component of his care to be funded by NHS.
- ◆ NSF for Older People 2001
 - ◆ Person Centred Approach – to include carers perceptions and needs
 - ◆ Single Assessment Process - Edward, Joyce and Clare to be fully involved in co-ordinated process of assessment and care planning

Integrated community care services - Edward and Joyce to receive prompt delivery of equipment in the home if they choose to remain there.

Intermediate care - to provide integrated services that will promote faster recovery in early weeks

Falls – effective health promotion and treatment

- ◆ Continuing Care 2001 – access to published eligibility criteria on continuing NHS care and explanation of rights to appeal.
- ◆ Supporting People 2001– may enable access to alternative care options such as extended extra care sheltered housing
- ◆ Fair Access to Care 2002 – if Edward meets appropriate risk banding can access social care services
- ◆ Discharge from Hospital, pathway process and practice 2003 – must recognise role of Joyce and Clare and ensure they are given choice. Should be seen as equal partners. Ward co-ordinator must be fully involved in all communication about discharge. Joyce and Clare should be informed as to name of ward co-ordinator. Decision to discharge must include multi-disciplinary team, as well as Edward, Joyce and Clare. Should be separate assessment of own needs as part of discharge process which is regularly reviewed.
- ◆ Community Care (Delayed Discharges etc) Act 2003 – NHS must give notice under Section 2 of this Act to social services of need for community care assessment and consult with Joyce and Clare.

Social Services must carry out assessment of Joyce's and Clare's needs to enable safe discharge as well as assessing Edward's needs. Needs must be kept under review.

No charge for intermediate care or equipment services. Free residential accommodation, personal care and carers services for first 6 weeks.

Summary Sheet 2

Policy context and Carer's rights

The standards for hospital discharge have, until recently, been contained within a variety of legislation, policy and guidance going back several years. This has made it very difficult for both carers and professionals to establish what the rights of carers are during the hospital discharge process. The new government guidance "Discharge from Hospital, pathway, process and practice" brings clarity to this issue and acknowledges the important role carers play and the need to help them maintain their own health and well-being. The following highlights key aspects within recent legislation, policy and guidance which relate to either hospital discharge, carers' rights or both.

Mental Health Act 1983 *Legislation*

Section 26 of the Act provides a formula which should enable the nearest relative to be identified, plus a number of rules which affect that decision. It gives the nearest relative a number of rights, including requiring an approved social worker to assess someone who might need to be admitted into hospital.

There is also reference to information sharing. The nearest relative/carer can be involved in the exchange of information with the patient's consent. If the patient has capacity to make that decision then that information cannot be shared.

The Code of Practice which accompanies the Act talks about the importance of collaborative working with the patient and the family and the encouraging of a sharing approach to information, particularly at discharge so that the family can understand the therapies and treatments.

Disabled Persons Act 1986 *Legislation*

This Act was the first statutory recognition of Carers. The Act required local authorities to consider the Carer's ability to care, however there was no duty to assist potential Carers, only those already providing substantial and regular care. It also excluded Carers caring for someone with a mental health problem.

Childrens Act 1989

Legislation

This Act is relevant to young carers ie. children under 18 who are caring for an adult or sibling with a disability, particularly where there may be relevant child protection issues. Under section 17(1) of the Act, social services have a duty to:

- ◆ Safeguard and promote the welfare of children within their area who are in need, and
- ◆ So far as is consistent with that duty, to promote the upbringing of such children by their families

NHS and Community Care Act 1990 *Legislation*

This legislation introduced the process of Care Management. It placed a duty on Local Authorities to carry out a community care assessment where someone appears to be in need. Need is defined at a local level leading to local eligibility criteria for social services. The Act also introduced the notion of an holistic assessment which takes into account the needs of family and friends. However, the Act confers relatively few rights on Carers themselves, although they can ask for an assessment of the person they care for, can be involved in the process and be informed of the result of the assessment.

The Direction on Choice 1992 *Guidance*

The Direction on Choice (LAC(92)27 and LAC (93) requires Local Authorities to take into account a person's preferred choice of accommodation when making arrangements for residential care. This choice is subject to a number of conditions:

- ◆ The preferred needs must be suitable to the needs of assessed by the Local Authority
- ◆ Would not require the Local Authority to pay more than they would normally expect to pay in order to meet the person's assessed needs
- ◆ The preferred accommodation is available
- ◆ The person in charge of the preferred accommodation provides it subject to usual terms and conditions of the Local Authority.

Carers (Recognition & Services) Act 1995

Legislation

This Act remedied a lot of the shortfalls of the Disabled Persons Act 1986 ie. placed a duty upon Local Authorities to assess (rather than just consider) the needs of Carers when the service user is subject to a

community care assessment and when the Carer is providing substantial and regular care. This duty applies to Carers of all ages and unlike the 1986 Act includes potential Carers and those Carers caring for someone with a mental health problem.

The accompanying policy guidance and practice guide stressed the role of housing, GPs and nurses in informing the Carer of the right to an assessment and to assist in the process. It also talked about equality of access, importance of making assessment accessible to those from an ethnic minority background and those with sensory impairment.

Modernising Social Services 1998 *Policy*

This White Paper introduced the promoting independence agenda and the importance of rehabilitative care. It is equally important to consider the role of the Carer within any rehabilitation programme that is put into place for the service user as well as the impact that that role might have on the Carer.

National Carers Strategy 1999

This intergovernmental policy was launched in February 1999 and provided a national policy framework at government level. The strategy reinforced the need for Carers Support Schemes or Carers Centres as well as breaks for Carers. The strategy is designed to help empower Carers, consider how they can be supported to remain in work, consider their health needs and look at the specific needs of ethnic minority carers and young carers.

The Strategy also announced the introduction of the Carers Grant which is ring fenced funding for Carers to take a break and is managed by Local Authorities. This grant has been extended until 31st March 2006. During 2003/4 Surrey will receive £1.8 million, rising to an estimated 3.2 million by 2006/7.

The Health Act 1999 *Legislation*

This Act enables local authorities and the NHS to work more closely together. The Act swept away any legal obstacles to joint working by allowing:

- ◆ Pooled budgets – this involves local health and social services putting money into a single dedicated budget to fund a wide range of care services

- ◆ Lead commissioning – either the local authority or primary care trust takes a lead in commissioning services on behalf of both bodies
- ◆ Integrated providers – local authorities and health authorities merge their services to deliver a one-stop package of care

Better Care Higher Standards *Guidance*

Published by the Office of the Deputy Prime Minister and DoH, this guidance promotes joint approaches on service standards and information provision across housing, health and social care for adults who need long term care, and for those who care for them. In Surrey the Better Care, Higher Standards Charter replaced the Citizen’s Charter and the Surrey Community Care Charter. A user friendly version provides clear joined up information for both service users and carers on what can be expected from health, housing and social care services in terms of services and standards.

National Service Framework for Mental Health 1999 *Policy*

This NSF sets out standards of care for adults of working age with mental health problems and their carers. People who receive specialist mental health services should be supported in accordance with the Care Programme Approach (CPA) and have a care co-ordinator who is responsible for ensure the delivery of a seamless service.

Standard Six of the NSF Mental Health entitled “Caring About Carers” states that all individuals who provide regular and substantial care for a person on the Care Programme Approach should:

- ◆ have an assessment of their caring, physical and mental health needs, repeated on at least an annual basis
- ◆ have their own written care plan which is given to them and implemented in discussion with them.

The NHS Plan: a plan for investment and reform 2000 *Policy*

The NHS Plan sets out major changes to the NHS in terms of funding, staffing and direction. It pledges to make the NHS more patient and carer centred with more joint working across the health and social care eg.

- ◆ Investment in respite care for carers
- ◆ Development of patient advocacy liaison service which will represent patients and carers more effectively. PCTs will have to ask users and carers their views

- ◆ Older people and their carers will receive an individual care plan when assessed
- ◆ Use of pooled budgets to promote closer working
- ◆ Pooling of information between health and social care through development of information technology

Carers and Disabled Children's Act 2000

Legislation

This legislation gave carers the right to ask for an assessment in their own right and is not dependent on the service user receiving an assessment. The Act also gave local authorities the power to provide carers with their own services following a carers assessment. They also have the power to provide vouchers or direct payments to carers so they can purchase their own services and thereby giving them choice. However local authorities are able to charge for these services.

Accompanying the legislation is a useful guide, *A practitioners guide to Carers Assessments*. It is designed to be a good practice tool aimed at staff carrying out carers' assessments. It helps to define what is meant by 'substantial and regular' and suggests that it is critical to establish with the carer if the caring role is sustainable and how great the risk is of the caring role becoming unsustainable. It suggests that when deciding if a carer is eligible for an assessment the impact of the whole caring situation and not just the amount of time per week spent caring should be taken into account. The guide refers to this as 'the impact test'.

The Act also highlighted for the first time Carers' needs in relation to training and work including Carers who are staff. The guidelines also state that there should be an interagency Carers' Strategy.

Free Nursing Care in Nursing Homes 2001

Guidance

This guidance enables all those funding their own care to become eligible for the nursing component of their care to be funded by the NHS. In April 2003, the responsibility for assessing and funding nursing care for all care home residents transfers from local authorities to the NHS. The guidance requires health and social care commissioners to work together to contract jointly with care home providers to meet individual's care needs.

National Service Framework for Older People 2001 *Policy*

This framework was published by the Department of Health in March 2001 and includes eight standards of care for older people's services.

1. Rooting out age discrimination ie. treatment to based on clinical need alone
2. Introduction of person centred care, including implementation of
 - a. *The Single Assessment Process (SAP)* which is a standardised assessment process across the health and social care sector and which puts the older person and their carer at the centre of assessment and care planning
 - b. *Integration of community equipment services* across health and social services to enable older people to be cared for more effectively at home. Integrated services and pooled budgets will deliver one local equipment service and will increase range and capacity of equipment provision within 7 days by December 2004
 - c. *Delivery of integrated continence services* by April 2003
3. Development of Intermediate Care to provide integrated services which will promote faster recovery, prevent unnecessary admission, support timely discharge and maximise independent living
4. General Hospital Care which aims to ensure older people receive appropriate specialist support and maximum benefit from being in hospital
5. Strokes to be reduced as well as ensuring those who experience a stroke receive prompt access to specialist support
6. Falls that result in serious injury to be reduced through health promotion as well as ensuring effective treatment and rehabilitation to those who have fallen
7. Mental Health in Older People to be improved through promotion of good mental health in older people and to treat and support older people with dementia and depression
8. Promotion of health and active life in older age to extend the life expectancy of older people.

Continuing Care: NHS and local council's responsibilities 2001

Guidance

This guidance requires all Strategic Health Authorities (StHAs) to review and agree new criteria for fully funded, continuing NHS health care. Primary Care Trusts and local authorities are required to be involved in

agreeing these new criteria and to have only one set of criteria across the StHA. Local Authorities and the NHS should also agree joint eligibility criteria for mixed packages requiring both health and social care.

Valuing People 2001 *Policy*

This new Government plan sets out ways for improving services for so that they can lead as independent a life as possible. A specific section of the plan is dedicated to family carers. It outlines how services need to develop to support parents and carers.

Needs and Services

- ◆ Family carers can get assessments of their own needs
- ◆ Families will be able to get advice from local services and there will be a single point of contact
- ◆ Agencies will be making short term breaks better
- ◆ The health needs of carers should also be looked at.

Working with carers

- ◆ All services and agencies should be working together with carers and not seeing them as a problem
- ◆ Carers will be able to look at how these changes are working

Older carers

- ◆ Lots of family carers are getting older and this causes worry to everyone. Local areas need to find out who the older carers are.
- ◆ There should be an agreed plan based on a person-centred approach for when the person with the learning disability wants something different or when the carer is unable to continue.

Carers from minority ethnic communities

- ◆ More needs to be done to address language and culture. Carers from minority ethnic communities must have their needs met.
- ◆ Agencies and services will work well with people from minority ethnic communities and will find out more about what they need.

Better information

- ◆ A new National Learning Disability Information Centre and telephone advice line will be set up. The Centre will provide help to all who need it. It will provide advice on the services and help people with learning disabilities need. It will also put carers in touch with local support groups.

More information on family carers, in a user friendly format,
can be found on the government website:

www.valuingpeople.org.uk/familymatters/howeare.htm

Supporting People 2001 *Policy*

This Government plan sets out important changes in the way housing and related benefits could be used to help vulnerable people achieve greater independence. The lead organisation is the local authority, but other health and social care organisations should contribute to the plans for developing housing-related services. This initiative has a key role to play in the development of alternative care options eg. extended extra care sheltered housing.

Fair Access to Care 2002 *Guidance*

This guidance requires social services departments to have reviewed and revised their eligibility criteria for adult social services by April 2003. The guidance requires the criteria to be graded according to four risk bands – critical, substantial, moderate and low and this will determine the speed and nature of services provided. Only one eligibility decision should be made and not for specific types of service.

Carers UK recommend that the separate eligibility criteria for services should be set up for disabled and for carers. They argue that if they are integrated, it is vital that there is no assumption that presence of a carer means that the disabled person is not at risk. They would also have to be very clear about the difference in risk between carers and the disabled person and not assume that a disabled person's risk is less simply because they have a carer. In other words it is important to look at the disabled person's risk first, consider the carer's risk second and finally come to a decision about individual risk.

It is also important to consider individual rights since these are also a central part of the Human Rights Act 1998. Article 8 for example states that an individual has a right to a private and family life.

Discharge from Hospital, pathway, process and practice, 2003 *Guidance*

The Department of Health have just published a replacement for the Hospital Discharge Workbook of 1994, which pulls together many of the the key messages that run through much of the above legislation:

- ◆ The need for statutory and independent agencies to work together in a co-ordinated way, both in terms of planning and delivery of health and social care
- ◆ Service users and carers who require services should be actively involved and fully informed in the assessment, planning and delivery of their care
- ◆ Promoting independence
- ◆ Effective clinical governance arrangements underpinning delivery of health care and Best Value Reviews ensuring effective provision and use of social care services

It highlights the concerns of Carers and looks for significant change in the way they are involved in hospital discharge:

A key message is to *“Recognise the important role Carers play and their own right for assessment and support ...the role of Carers must be taken into account in any discharge planning”*

It goes on to state that Carers must be *“given a choice about undertaking a caring role”* and highlights the need for *“engagement and communication with the Carer”*. Pre-admission assessments should consider *“The Carer’s worries and concerns about how he or she is coping”*.

There will be ward based co-ordinators who :

- ◆ will engage the carer and make arrangements for carers assessments if appropriate”
- ◆ make arrangements to see the Carer separately regarding their own needs
- ◆ finalise the transfer/discharge arrangements 48 hours before discharge and confirm with patient and carer/family.
- ◆ Ensure the special needs of Young Carers are identified

Community Care (Delayed Discharges etc) Act 2003

A number of new duties have been placed upon the NHS and local authorities relating to the discharge of patients under this Act. The main effects of the Act include:

- ◆ Part 1 of the Act will introduce fines (“reimbursement”) for a social services authority for each day an NHS patient’s discharge from hospital is delayed and when the social services authority is responsible for that delay. The liability to pay will arise where the authority have not put into place the community care services for a patient or services to an individual’s carer, which the authority have assessed the patient and the carer needing in order to be discharged safely. It is intended that the social services authority will use the period prior to admission or following admission but before discharge to assess the patient and the carer’s needs and arrange services promptly.
- ◆ The NHS body with responsibility for the patient are required to inform the authority of their need for community care services in order to be safely discharged. They need to make it explicit to the local authority that they are giving notice under section 2 of the Act. Notice should not be given more than 8 days before the day of admission.
- ◆ The NHS body have a duty to consult with the patient and the carer before issuing a notice to the social services authority of the patient’s likely need for community care services. They only have to consult with the carer if they know who the carer is and if it is practical to do so.
- ◆ Following issue of a section 2 notice the authority must carry out an assessment of the patient’s community care needs and also the needs of any carer of the patient in order to make the discharge safe. This applies whether or not the patient and carer have been assessed before. The authority must keep their needs under review so as to cover situations where the patient or carer needs have changed.
- ◆ The social services authority must be informed of any changes to the discharge date, so that they can make corresponding changes. The NHS body must consult with the authority before deciding which health care services will be provided to the patient upon discharge so as to avoid duplication or gaps.
- ◆ The Act provides for a minimum interval for social services to put services into place. The minimum interval starts on the day after the social services authority receive notice under Section 2. The authority must be given at least 2 further days to assess the patient and carer

needs and put into place sufficient services to allow safe discharge. Sundays and public holidays cannot be counted.

- ◆ Strategic Health Authorities are required to set up dispute bodies to deal with disagreement about readiness for discharge and the responsibility for delay.
- ◆ Part II of the Act removes the discretionary power of local authorities to charge for certain community care and carers' services. It removes the discretionary charging power in respect of community equipment services (up to value of £1,000) and intermediate care. Certain services cannot be made free of charge for more than 6 weeks ie. residential accommodation, personal care in the home or carer services.

Mental Health Services will not come under the scope of this legislation at present.

Originally the Government wanted to implement the legislation by April 2003, however a compromise was reached with the Opposition. Part 1 of the Act will commence in October 2003 including Carer's enhanced rights alongside the serving notices of discharge. However, NHS will not start charging local authorities for every delayed discharge until 1st January 2004. £50 million will be given to local authorities in the run up to implementation to help change practice and ensure support is in place.

LEGISLATION/GUIDANCE	RELEVANT?	IF SO, WHY?
Mental Health Act 1983		
Disabled Persons Act 1986		
Childrens Act 1989		
NHS & Community Care Act 1990		
The Direction on Choice 1992		
Carers(Recognition & Services) Act 1995		
Modernising Social Services 1998		
National Carers Strategy 1999		
The Health Act 1999		
Better Care Higher Standards		
National Service Framework for Mental Health 1999		
The NHS Plan 2000		
Carers and Disabled Children Act 2000		
Free Nursing Care in Nursing Homes 2001		
National Service Framework for Older People 2001		
Continuing Care: NHS and Local council's responsibilities 2001		
Supporting People 2001		
Valuing People 2001		
Fair Access to Care 2002		
Discharge from Hospital, pathway, process and practice 2003		

Community Care (Delayed Discharges etc) Act 2003		
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CARERS AND HOSPITAL DISCHARGE – WHAT TO EXPECT

Until recently the standards for hospital discharge have been contained within a range of legislation and guidance going back several years. This has made it very difficult for patients, carers and professionals to establish what standards to expect throughout the hospital discharge process. Recent Government Guidance “Discharge from Hospital: Pathway, Process and Practice” and the Community Care (Delayed Discharges etc) Act 2003 are designed to provide a coherent set of standards.

So what should you now expect as a Carer according to the new Government guidance?

1. Recognition of your role and expertise

“Under stressful circumstances, such as an emergency admission, it is even more important to recognise the role of the carer from the start of the process in order to ensure that all the stages are well managed.”

“patients and their carers are the ‘experts’ in how they feel and what it is like to live with, or care for, someone with a particular condition”

2. To be fully involved at all stages of the process as an equal partner

“It is essential that any assessment and care planning process, continually engages the patient and their carers”

“The development of patient centred care requires the transformation of the professional/patient and carer relationship so that they are fully involved as partners at all stages of discharge planning.”

“The power and control exhibited by many professionals needs to change from one of professional dominance to one where power and control is shared.”

3. Early engagement with you

“Early engagement and identification of their worries, concerns and aspirations are critical if individuals are to be helped to reach their goals.”

4. To be involved in decision to discharge

“This is a decision made by the multi-disciplinary team when considering all the factors, which will include the relative safety of remaining in hospital or being elsewhere and the patient’s and carer’s view of these risks.”

“It is important to involve the carer as part of the team as they will have expertise regarding the patient’s home environment.”

5. To be provided with information

“Patients and their carers (are to be) provided with information, both verbal and written, and in a range of formats”

“Attention should be directed to ensuring that carers are informed about the support networks and services that may be available to them”

6. To have a choice about whether to care

“Ensure that the carer has a choice about caring and that, if they choose to care, they are supported to do so in a way that promotes their health and well being.”

“(Carers) should be given time to consider the options in making what are often life-changing decisions. These may be about how much and what type of care and the impact on their life and commitments and the financial consequences of the caring role.”

7. Pre-admission screening/assessment of the patient to help you prepare

“Pre-admission screening should be routine for all elective admissions. This period of preparation helps patients and their families understand how they can help themselves and plan for their return home”

8. Separate assessment of your own needs and your own Care Plan

“Care must be taken to discuss with carers their concerns and make arrangements for a full assessment where appropriate. Consideration at this stage should include any risk to their own health, risk of harm to carer and risk of loss of employment as well as helping carers to cope with support.”

9. Consideration of your need for short term breaks

“The assessment and review process should consider the need for short-term break from caring. Additional resources have been provided under the Carers Grant for this purpose”

10. Recognition of young carers needs

“It is vital that every effort is made to ensure that the family has sufficient services to ensure that children are not left with unacceptable caring responsibilities that effect their welfare, education or development.”

11. A co-ordinated hospital discharge process

“On admission to the ward a named individual from the ward staff should be identified to co-ordinate a stages of the patient journey.....Patients, their carers and/or relatives should be aware of who this individual is, and how to contact him or her.”

“Care co-ordinator key tasks ...engage the carer and make arrangements for carer assessment if appropriate. Make arrangements to see the carer separately regarding their own needs.”

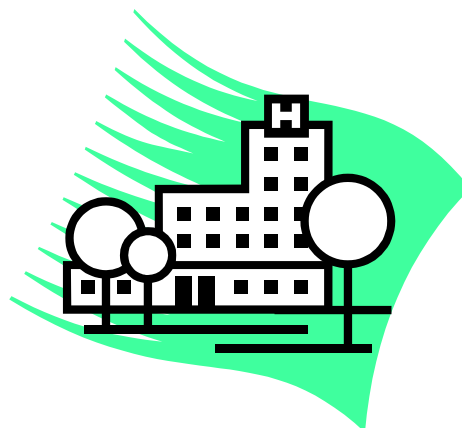
“Implementation plans for the single assessment process, include interface issues to improve continuity between community and acute services to reduce red tape”

12. To be supported by trained staff

“Senior managersneed to develop an education/training programme for staff in discharge planning to include working with carers”

What should you expect according to the new Community Care (Delayed Discharges etc) Act 2003?

1. **NHS to refer you and the person you care for to Social Services for assessment where there are additional community care needs upon discharge**
2. **NHS to consult you and the person you care for about the referral to Social Services**
3. **Social Services to assess promptly the community care needs of the person you care for once NHS have given notice and to arrange services required for safe discharge. (Social Services will always be given at least two full working days notice of discharge to give sufficient time to assess and put in sufficient services. If Social Services delay the discharge they will have to make a payment to the NHS.)**
4. **Social Services to provide separate assessment of your own needs whether or not you have received an assessment before.**
5. **Social Services to keep your needs and the needs of the person you care for under review to take account of any changes during hospital stay**
6. **NHS and Social Services to communicate effectively with one another about any changes to discharge date.**
7. **Free provision of certain community care and carer’s services. The Act removes Social Services discretionary charging power in respect of community equipment services and intermediate care. Certain services cannot be made free of charge for more than 6 weeks ie. residential accommodation, personal care in the home or carer services.**



ACTIVITY TWO – POLICY CONTEXT

This second activity looks at the legislation, policy and guidance relating to hospital discharge and considers the legal rights of carers during the process. Work in small groups using the following case study and using pages 7-13 in the guidance pack “Discharge from Hospital, pathway, process and practice” and Summary Sheet 2 identify:

- ◆ The rights of Joyce and Clare
- ◆ The legislation, policy and guidance that underpin those rights

Two weeks ago Edward was admitted to hospital with a viral infection and some bed sore complications.

Edward, aged 82, is severely disabled with rheumatoid arthritis. His wife Joyce, aged 80, is physically frail herself and is finding it difficult to cope with her husband’s increasing care needs at home. Their daughter Clare, is in full time work and is a single parent with two children. She calls every day on her parents to keep an eye on them.

The ward has just informed Joyce that the Consultant considers Edward medically fit to be discharged, and that she should make arrangements to come and collect him as soon as possible. A distressed Joyce telephones Clare for help, saying that there is no way she can cope if Edward is discharged. Indeed she feels that she would like to consider sheltered housing or even residential care for them both because of her own deteriorating health.

Session Three – facilitator notes

Introducing session three:

Before considering ways of how to effectively involve carers in the process of hospital discharge it is important to consider the benefits of involving carers not just from the perspective of the carer, but also from the perspective of the patient and professionals.

Carrying out activity three:

This third activity is designed to encourage participants to think broadly about the benefits of involving carers in the process of hospital discharge. Divide the main group into three smaller groups. Using activity sheet three ask group one to consider the benefits of involving carers from the carers perspective, group two to consider benefits from the patient perspective and group three from the professional perspective.

Take feedback from groups, jotting down key words from each group under the three headings Carer, Patient and Staff.

Give out Summary Sheet three.

Show OVERHEAD SIX to demonstrate how meaningful involvement of patients and carers requires a more person centered approach and a shift in balance and control.

BENEFITS OF INVOLVING CARERS DURING HOSPITAL DISCHARGE

TO CARER	TO PATIENT	TO STAFF
<p>Greater sense of control Equal Partners Increased confidence Recognised and valued as an individual Opportunity to explore impact of becoming a carer or continuing to care Enables choice Information on how to care Training in how to care Contacts made Clarification of responsibilities Obtain services/support for self eg breaks/vouchers Financial advice/support Alleviate guilt Identify young carers Reduces risk to own health Knowing what to do in a crisis Knowledge on medication Develop coping strategies Discuss own problems in depth Encouraged to look at own needs Greater understanding of what to expect</p>	<p><i>Encourages communication between patient and carer</i> Holistic approach to patient's needs Encourages sharing of information Reduces risk upon discharge Identifies warning signals Consistent approach to care upon discharge Reduces stress Improved family relationships Avoidance of readmission</p>	<p>Gain the full story Not making assumptions Helps to focus professional effort Reduces staff anxieties Improved discharge performance Reduction in unnecessary admissions More responsive service Helps identify patient needs Helps to know when to refer on Improved staff/family relationships Greater job satisfaction Better discharge planning Encourages creative thinking Better collaborative working/partnership approach</p>

ACTIVITY THREE – BENEFITS OF INVOLVING CARERS

This third activity looks at the benefits of involving carers during the hospital discharge process from 3 different perspectives. Your group will have been asked to complete one of the following columns.

BENEFITS OF INVOLVING CARERS FROM PERSPECTIVE OF:		
Carer	Patient	Staff

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ACTIVITY FOUR – ENABLING CARER INVOLVEMENT AND CHOICE

In your group you will have been asked to consider ONE of the following case studies and to answer the following questions:

1. What factors might deprive the carer of their involvement in the discharge process and being able to make informed choices?
2. What do you think could be done to address these factors so as to enable more carer involvement and choice and by whom?
3. Consider the extent to which carers are involved and given choice in your own local hospital. What simple, practical changes could be made to enable carers to be more involved during the discharge process and to be offered choice.

Pages 35-42 of the DoH guidance as well as Page 87 might help trigger discussion.

CASE STUDY ONE

Mr Khan is 45 years old suffering from Huntingtons Disease and has been admitted into the mental health unit of the local hospital. The disease has progressed to such an extent that he is now using a wheelchair, can only walk very limited distances as his balance is poor, is finding it increasingly difficult to concentrate on intellectual tasks and is having difficulty feeding himself or swallowing.

Mr Khan is living in a small council flat with his wife and ten year old daughter. Their bathroom is upstairs and there is no toilet downstairs. Mr Khan cannot climb stairs so he lives and sleeps in the sitting room with Mrs Khan carrying out all of his care without support or any aids/equipment. He came to Britain with his Muslim family as a small child and has a good command of English. His wife has limited English as she only moved to Britain when marrying.

Mr Khan was admitted to hospital due to serious loss of weight. In hospital he is put on a liquid and soft food diet, his weight has been built up again and he is now medically fit enough to be discharged. Mrs Khan appears agitated at the prospect of his return home.

CASE STUDY TWO

Ted Bleach is 75 years old and is married to Mary, 70 years old. Ted has prostate cancer and is terminally ill. Ted was admitted to hospital some months ago and was examined by General Medical, Urology and Oncology hospital doctors. He was discharged home on that occasion with painkillers and a catheter. Ted and Mary refused a home visit.

Ted and Mary live in a first floor sheltered housing flat. There are limited facilities at the flat with no aids or adaptations. Mary is struggling to keep the flat tidy and clean, the cooker and washing machine is broken. It has become so cluttered that the state of the flat is preventing Ted from moving around easily. Ted's legs have become quite swollen and he has experienced faecal incontinence on occasions which they have both found distressing. The warden checks daily to see they are managing, but neither Ted or Mary have talked to her about their anxieties. She has noticed, however, how thin Mary has become.

Two weeks ago Ted was readmitted to hospital following a frightening episode at night when he became very short of breath. Mary is very close to her husband and insists on staying with him throughout his stay, including at night. Ted appears quite passive and quiet, whilst Mary has on occasions been aggressive with staff and has kept her distance from professionals.

The hospital doctor now considers Ted ready for discharge. His shortness of breath appears to be limited to times of exertion and anxiety and he is able to walk the length of the bay unassisted and without aids. He has been prescribed medication for the swollen legs and he still requires a catheter. There has been no evidence of faecal incontinence in hospital. Once again they have both refused help in the home following discharge. Instead Mary has made it clear that she wants Ted to remain in hospital until he is more able and she can manage his care by herself. Staff have found it difficult to establish Ted's wishes.

CASE STUDY THREE

Mrs Groves, a 78 year old lady with Parkinson's disease was admitted to hospital following a fall. She was found to have a fractured hip, which was treated with traction, because of her poor general condition.

She has been confused at times before admission, but her confusion has worsened during her stay in hospital, both on the acute ward and during the long period of rehabilitation. Her mobility is poor, and she requires two people to move her from the chair although once up she can walk for short distances without help. She is doubly incontinent and frequently incontinent when moved. She has developed a pressure sore on her sacrum whilst in traction, but this is now healing.

Mrs Groves lives with her husband in their own bungalow. Mr Groves is anxious to have her home so he can care for her as he has always promised. The ward co-ordinator and other professionals within the multi-disciplinary team are recommending nursing home care. Although Mrs Groves has received a community care assessment and continuing care assessment, no carers assessment has been carried out.

FACILITATOR NOTES FOR CASE STUDY ONE

Possible factors depriving carer of involvement/choice:

- ◆ Mrs Khan has difficulty asking questions and communicating own needs due to limited English. Although Mr Khan speaks English well his disease also hampers his ability to communicate to express wife's concerns
- ◆ Mrs Khan has limited understanding of the 'system' and 'process' and is confused by roles, uniforms and titles.
- ◆ No referral has been made to social services for a community care assessment and therefore Mrs Khan has not been offered a carers assessment, which would address her own health needs, finances, parental responsibilities, accommodation, breaks and social contact.
- ◆ No home visit has been carried out to assess impact of caring on Mrs Khan without package of support. Mrs Khan is caring for Mr Khan using bed in middle of sitting room, and commode. There are no downstairs washing/toilet facilities or special aids/equipment. Accommodation/environment is generally unsuitable requiring referral to housing.
- ◆ Mrs Khan has not been offered an early separate conversation about her concerns or worries, using services of an interpreter.
- ◆ Assumptions may have been made about wider family providing support and care.
- ◆ No written information has been given to Mrs Khan in own language about disease, prognosis and how to care.
- ◆ Mrs Khan is exhausted due to 24 hour nature of care, making it harder for her to challenge or be assertive. Sees it as her duty to take primary role in his care and reticent to ask for help. Husband's family expects Mrs Khan to take on burden of caring role. Mr Khan worried about agreeing to outside help with personal care as reluctant to have intimate care provided by woman. This places further pressure on Mrs Khan.
- ◆ There has been no consideration of wider family and particular ten year old daughter. She is distressed by her father's deterioration and she is not allowed to use sitting room due to personal nature of care ie. cultural issues not addressed. Impact of being young carer may be significant eg. education and social issues.
- ◆ Both Mr and Mrs Khan are worried about whether daughter has inherited disease.

Possible ways of enabling involvement/choice:

- ◆ Written information available in mother language on medical condition, how to care, sources of help, continuing care criteria etc. Also information which addresses anxieties around hereditary nature of disease
- ◆ Use of interpreter to explain process of discharge, the system and roles and responsibilities
- ◆ Ensure referral to Social Services for Carer's assessment – explain value and purpose to Mrs Khan in own language
- ◆ Draw up care plan with Mrs Khan which addresses caregiving tasks, her involvement in the planning of treatment and care, support for herself, her own well being, risk and safety etc.
- ◆ Possible young carers assessment required.
- ◆ Advocate/professional support during meetings to ensure voice is heard
- ◆ Home visit to address environmental issues
- ◆ Avoiding assumptions around cultural issues eg. family will care
- ◆ Explore possibility of male care worker in the home
- ◆ Ward co-ordinator to ensure discussion with Mrs Khan throughout process
- ◆ Identify training for Mrs Khan eg. moving and handling in the home

FACILITATOR NOTES FOR CASE STUDY TWO

Possible factors depriving carer involvement and choice:

- ◆ *Mary is unwell herself, has frequent stomach upsets, has no appetite and is losing weight.*
- ◆ *Mary is frightened about how to care and what his care needs might be in the future. She is worried about both the catheter care and the faecal incontinence. This fear manifests itself in anger at times.*
- ◆ *Mary is also worried about the fact she cannot cook properly and is unsure what to prepare in the way of food for Ted. She is also worried about the laundry and how to manage Ted's incontinence but doesn't want to say anything in front of Ted on the ward.*
- ◆ *Mary feels very intimidated by the large number of professionals she comes into contact and this again leads to a defensive reaction. No one person to relate to.*
- ◆ *Mary has as a consequence become labelled as 'difficult' which in turn hinders communication with professionals.*
- ◆ *The flat is in a terrible mess and Mary is embarrassed about professionals coming to her home – they might think she is 'dirty'. Hence refusing home visit and any community services.*

Possible ways of enabling involvement and choice:

- ◆ *Ward Co-ordinator to ensure early separate conversation with Mary to identify initial worries and concerns. Explore use of advocate and*
- ◆ *Explain carefully purpose and value of community care assessment and carer's assessment*
- ◆ *Avoiding assuming carer is coping or is just being 'difficult'. Explore causes of aggressive behaviour*
- ◆ *Provide verbal and written information on medical condition, how to care, sources of help, discharge plan etc. in plain English.*
- ◆ *Explain the different roles and responsibilities of the multi-disciplinary team and the importance of the carer role within that team*
- ◆ *Explain risks associated with husband remaining in a hospital environment eg. cross-infection, psychological, increased risks of falls*

- ◆ *Assess with Mary the risks to here of continuing to care without support eg. health, social isolation, further deterioration of environment*
- ◆ *Identify her own training needs*

FACILITATOR NOTES FOR CASE STUDY THREE

Possible factors depriving carer involvement and choice:

- ◆ Professionals involved in a complex case of this nature may feel anxious about discharging into the community due to perceived level of risk. Power balance likely to be in favour of the MDT therefore more difficult for Mr Groves preferences, and those his wife, to be heard.
- ◆ Mr Groves not provided with information on continuing care criteria, how wife meets or doesn't meet those criteria, the Direction on Choice or Free Nursing Care in order to make an informed choice.
- ◆ Worries about financial impact of nursing home care and guilt at having failed in some way may prevent Mr Groves considering this option.
- ◆ Gender assumptions might be made about his ability to care at home and 'expertise' undervalued.
- ◆ No Carer's assessment has been offered or carried out, thereby providing an opportunity to explore fully the impact of caring for his wife at home, including his own health, so that he can make an informed choice.
- ◆ As a consequence no care plan for Mr Groves considered. Care Plan would address ways of managing risks to him if caring at home.

Possible ways to enable Carer Involvement and Choice

- ◆ The Multidisciplinary team to view Mr Groves as integral part of team and as equal partner. Expertise needs to be recognised and needs to be fully involved in decision making process. Person centred care requires team to find out from Mr Groves what Mrs Groves would want, if she is unable to express her own wishes as a result of mental incapacity.
- ◆ Assumptions should not be made as to his ability to care.
- ◆ Inform Mr Groves of his right to his own assessment and its value and purpose

- ◆ Multi-disciplinary team with Mr Groves, to carry out risk assessment, based on decision that she returns home. Identify risk factors, likelihoods and values of outcomes from different perspectives ie. staff, Mrs Groves, Mr Groves.
- ◆ As part of carers assessment process, assess risks to Mr Groves of wife returning home.
- ◆ Provide verbal and written information on continuing care criteria, Directions on Choice and free nursing care.
- ◆ Ward co-ordinator to provide one point of contact for Mr Groves and develop rapport
- ◆ Offer advocacy or professional support during multi-disciplinary meetings to ensure Mr Groves voice is heard.

Session Four – facilitator notes

Introducing session four:

Having considered what the benefits are of involving carers it is now important to think about what the possible constraints might be to their involvement during the hospital discharge process and ways of overcoming those difficulties.

Carrying out activity four:

This fourth activity is designed to encourage participants to think about ways of enabling carers to be fully involved in the hospital discharge process taking into account practical constraints. Divide the group into three groups and allocate one of the following case studies to each group. Ask a member of each group to jot down key bullet points onto a sheet of flipchart to enable feedback.

Take feedback from each group and summarise key learning points using OVERHEADS SEVEN, EIGHT, NINE and TEN

Hand out Summary Sheet Four.

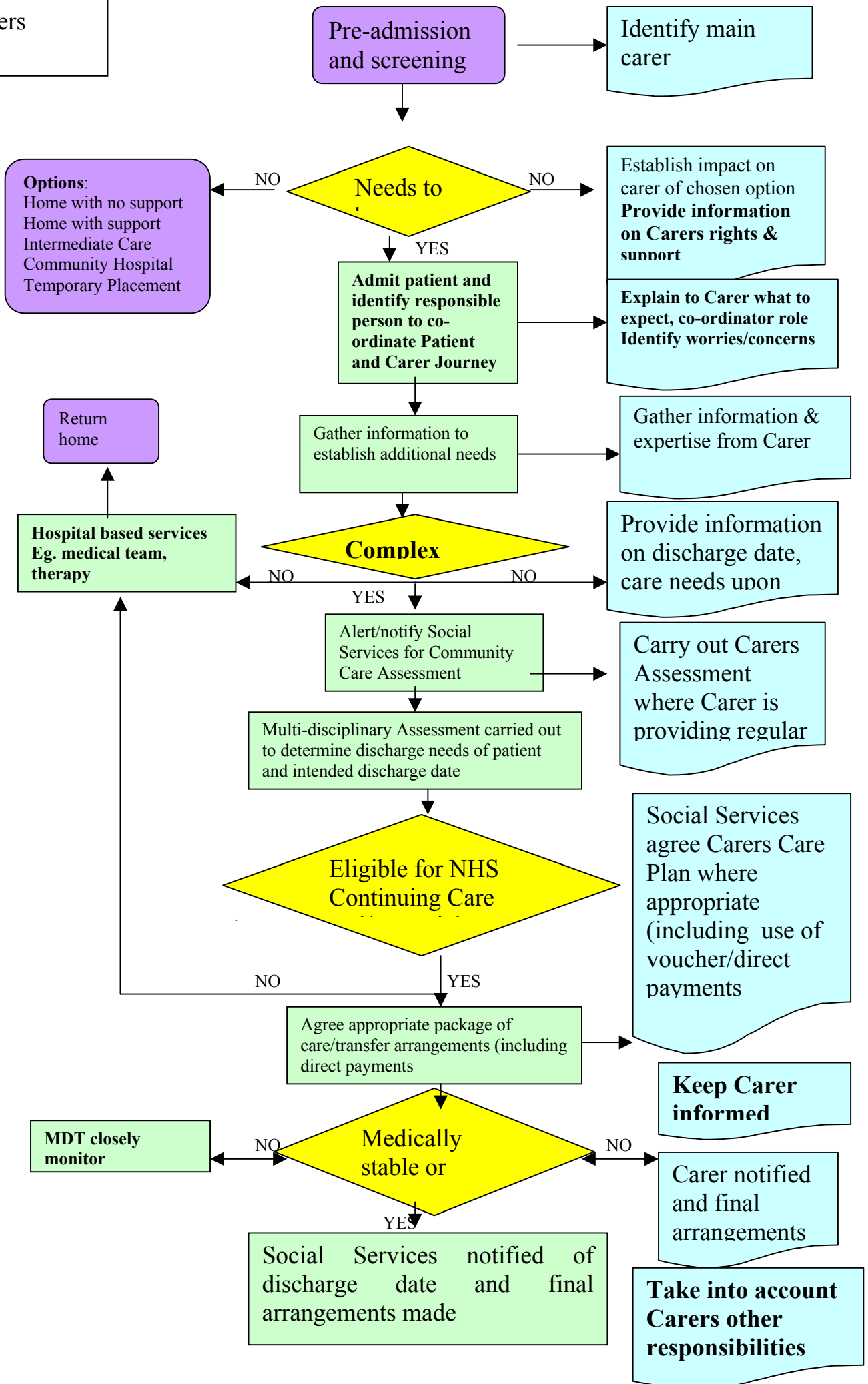
Summary Sheet 4

Ways to enable Carer Involvement and Choice

1. *View the Carer as part of the multi-disciplinary team and as **equal partners**. It is important to include the carer in team discussions as they will have the expertise regarding the patient and their home environment. The development of person-centred care requires a change in the professional/carer relationship so that they are fully involved in all stages of the discharge process.*
2. *Actively seek permission early on from the patient to **share information** with their Carer. Explain the benefits of involving their Carer in their discharge plan and what the disadvantages might be of not actively involving them. Where patients refuse permission, carers must be informed of this and their right to their own assessment emphasised. Where the Carer's needs or wishes conflict with the patient's, staff should review the care plan and endeavour to find a sensible solution that will satisfy all concerned.*
3. Provide **verbal and written information** about the discharge plan to the Carer. Think about putting together a folder of information for them to take home. If they are to care appropriately, Carers need information on the medical condition of the patient, medication and other treatments, how to care, sources of help, continuing care criteria, charging policies, access to interpreters or advocates, notice of discharge, transport arrangements, complaints, benefits, and very importantly the discharge plan, etc.
4. Inform Carers of their **right to an assessment** of their own needs and in the case of a carer caring for a person with mental health needs who is on care programme approach, also their own care plan. Carers may have very different needs from the patient and it is important that these needs are explored with them. A carer's assessment checklist can be found on P43 of the DoH hospital discharge guidance.
5. Assess with the Carer the **risks of caring**. The Carer will need time to consider those risks and to think about the different options open to them, the potential impact on their lifestyle, health, employment and finances.

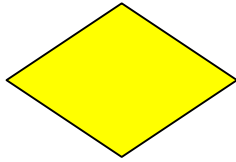
6. **Ward co-ordinator** to develop strong links with the Carer. Ward Co-ordinators could set up weekend or evening ‘surgeries’ or meetings for Carers, relatives and family.
7. Consider ways of shifting the **power balance** more in favour of both patients and Carers. For example, attending discharge planning meetings can be an intimidating experience. Offering advocacy or professional support during those meetings might help even up the odds. Provide appropriate support and information to enable patients and carers to be involved in the development of hospital discharge strategies and policies and to put their point of view across.
8. **Carers’ training** needs also should be identified. For example advice on back care and appropriate ways of moving and handling, will be critical to the continued health of the carer. Demonstrate proper use of equipment prior to discharge and put in place follow up arrangements to ensure it is being used correctly.
9. Avoid making **assumptions** about the Carer’s willingness or ability to care. Too often professionals simply assume the Carer will take on the caring role upon discharge or continue caring as before.
10. There needs to be an **early conversation** with the Carer as to their own worries, concerns and aspirations.
11. Provide information in a **range of formats and languages**. Any form of communication must take into account the individual’s ability to understand and absorb information. The same information should be available in a range of languages as well as plain english. It should also be presented in large print, Braille and British sign language. Other formats such as CD-rom, audio-tapes and visual formats should also be considered. For some Carers an interpreter or advocate may be necessary to ensure full understanding.

The Carers Journey

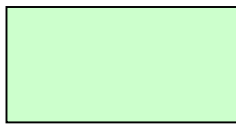




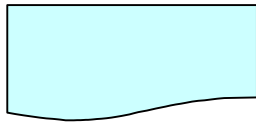
Start/end of journey



Decision



Operational Step



Carer's Process

Session Five – facilitator notes

Introducing session five:

Carers need to have good quality information on services and support available to them during and following discharge from hospital. Therefore staff need to keep up to date information on Carers' services/support which is available in range of formats and languages. Alternatively they should signpost to a colleague who would be able to provide such information eg. Carer Support Worker.

Carrying out activity five:

This fifth activity is designed to encourage participants to share information about the different support/services that they are already aware of. Simply write the heading CARER SUPPORT SERVICES in middle of a piece of flipchart paper and ask large group to highlight those services/support for Carers that they are aware of. Record services/support highlighted on the flipchart around the heading. As you go along check out with participants their understanding of the nature of each service highlighted as well as how to access.

Summarise using OVERHEAD ELEVEN.

Hand out a Summary sheet appropriate to your area of local services/support with contact numbers and email addresses

Session Six – facilitator notes

Introducing session six:

Previous sessions have established the benefits of involving Carers and enabling choice for them as well providing an opportunity to consider ways to improve the experience for Carers. We need to reflect now on what needs to happen at a local level in order to embed these principles in our own day to day practice.

Carrying out activity six:

This sixth activity provides an opportunity for participants to reflect further on what happens at a local level and to decide on an action plan for change. For this activity ask participants to work in groups with colleagues with whom they have regular contact. Ask participants to reflect back on the Activity Four when they were asked to consider the extent to which carers are involved and given choice in their own hospital. Ask each group to focus on **three** areas of concern and develop an action plan to address each of these areas, using Activity Sheet Six. Stress the importance of SMART objectives ie. specific, measurable, attainable, realistic and timed. Ask groups to think about any ‘quick wins’ which could help motivate staff and help change our approach to our work with carers.

Ask for verbal feedback on **one** area of change from each group.

ACTIVITY SIX – ACTION PLAN

Reflect back on Activity Four when you were asked to evaluate the extent to which Carers are involved and given choice during hospital discharge locally and to think about some simple changes to improve the Carer experience. Decide in your group on **three** priority areas of concern and complete the following. Remember objectives must be SMART (Specific, Measurable, Achievable, Relevant and Time bound) eg. Ward Co-ordinators to have information for Carers on their rights to an assessment readily available and in different formats and languages.

Objective	Actions	Who involved	Timescale	How measured/ monitored
1.				
2.				
3.				