Involving Carers in Discharge Planning

A practical guide for health and social care practitioners involved in discharge planning from hospital.
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About Us
Health & Social Care Integration Division is part of the Scottish Government, and is responsible for overseeing the integration of health and social care services across Scotland.

Integration is the most significant change to health and social care services in Scotland since the creation of the NHS in 1948. With a greater emphasis on joining up services and focusing on anticipatory and preventative care, integration aims to improve care and support for people who use services, their carers and their families.

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About the guides
This is one of a range of good practice guides focusing on the various aspects of discharge planning for patients with ongoing health & social care needs after discharge. This guide includes a range of practical hints, tips and useful resources from a range of sources.

Health & Social Care practitioners may wish to use or adapt all or part of this guide to make local improvements. However, the guide does not aim to override any existing local good practice already in place.

Feedback and Good Practice
You can also submit your comments, questions or examples of good practice using our Feedback Form.
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Involving Carers in Discharge Planning

A practical guide for health and social care practitioners involved in discharge planning from hospital.

Introduction

This is one of a range of practical good practice guides focusing on the various aspects of discharge planning for patients with ongoing health & social care needs after discharge.

Section 28 of the Carer (Scotland) Act 2016 places a new duty on Health Boards to involve carers in the discharged planning procedures of patients who may require on-going care after discharge from hospital.

This guide aims to offer practical advice to health and social care professionals involved in the discharge planning of people with ongoing health and social care needs, after discharge. It includes a range of practical hints, tips and useful resources from a range of sources.

Health & Social Care practitioners may wish to use or adapt all or part of this guide to make local improvements. However, the guide does not aim to override any existing local good practice already in place.

Carers (Scotland) Act 2016

Section 28 of the Act states that:

1) Each Health Board must ensure that, before a cared for person is discharged from hospital, it involves any carer of that person in the discharge.

2) A Health Board fulfils the duty in subsection (1) by –
   a) Taking such steps as it considers appropriate to –
      i) Inform the carer, as soon as reasonably practicable, of the intention to discharge the cared-for person, and
      ii) Invite the carer to give views about the discharge of the cared-for person, and
   b) Taking account, so far as is reasonable and practicable to do so, of any views given by the carer in making decisions relating to the discharge of the cared-for person.

3) This section applies only –
   a) Where the Health Board can identify without delay that a person is the carer of the cared-for person, and
   b) Where it appears to the Health Board that the cared-for person is likely to require care following discharge.
The Public Bodies (Joint Working) (Scotland) Act 2014
The Public Bodies Act requires each Health Board and Local Authority to delegate some of their functions to Integration Authorities within their environs. This will include delegating most responsibilities for carers support and engagement. Delegating responsibility for health and social care functions to the Integration Authority, creates a single local system for strategic commissioning of health and social care services, built around population needs, and supports whole system redesign in favour of preventative and anticipatory care in communities.

As well as, at a minimum, all of adult social care, primary care and mental health, Integration Authorities are also responsible for the strategic commissioning of services most commonly associated with the emergency care pathway, i.e., hospital specialties that exhibit a predominance of unplanned bed day use for adults.

RESOURCES

The Carers (Scotland) Act 2016
The Public Bodies (Joint Working) (Scotland) Act 2014
Health & Social Care Integration Advice Notes
NICE Quality Standard; Transition between inpatient hospital setting and community or care home setting for adults with social care needs
Why involve carers in discharge planning?
Carers should be treated as equal partners in the care of those they care for. They can play a significant role in helping people with health and social care needs return home after a hospital admission. They know the people that they care for better than anyone else and can provide information about the person’s needs and circumstances beyond medical conditions or physical needs. This means discharge planning can be more comprehensive and may reduce the likelihood of the person being readmitted to hospital.

If care is planned without the input of the carer, an opportunity has been lost. Therefore, engagement and co-operation with carers is an essential part of good patient care.

Furthermore, co-operation is needed from carers to effectively implement any future care plan. Involving the carer when devising a care plan, and listening to the carer’s views, is likely to result in better outcomes for the patient and carer.

The Carers Charter
As required by section 36 of the Carers Act Scottish Ministers have prepared a Carers’ charter, to help carers understand their rights and responsibilities under the Act. A link to the Carers Charter can be found in the Resources section below.

RESOURCES

The Carers’ Charter

Why can’t people stay in hospital?
A person is not entitled to remain indefinitely in hospital once they are ready for discharge. Integration Authorities should take robust action to ensure that people are not inappropriately delayed in hospital if care, appropriate to their needs, is available in the community.

Health and Social care staff should work with the patient, family and carers to assess the person’s long-term needs following discharge, and provide appropriate services to meet those needs. People do not have the right to choose to stay in hospital, where this goes against best clinical practice.

3 weeks of bed rest is equivalent to 30 years of ageing
There is clear evidence that an unnecessary, prolonged stay in hospital can be detrimental to a person’s physical and mental wellbeing and can result in:

- A sense of disconnection from family, friends and usual social network leading to boredom, loneliness, hopelessness, confusion and depression.
- Increased susceptibility to hospital associated infection and a higher risk of delirium, malnutrition, pressure sores, muscle wastage and falls.
- Loss of confidence and ability to cope at home, resulting in a premature shift to permanent care, particularly for people with dementia.
- Distress to the patient, family carer or proxy as they are unable to plan ahead for the discharge date and have to spend more time and money on regular, frequent visits to the hospital.

70 percent of older patients can acquire pressure ulcers within 2 weeks of a hospital admission.
Identifying and working with carers

Early identification of carers allows them to continue in their carer role for longer, with better outcomes for them and the person they care for.

A key time to identify carers is when the person they care for is admitted to, or discharged from, hospital.

Who cares?
- A carer could be a partner, family member or friend. They may not live with the person they care for and may have other responsibilities such as work and dependent children.
- Carers can be any age, including under 18.
- Parents are carers if the care they give their children is needed for reasons other than the child’s age.
- The carer could be the person who brings the patient to hospital, visits then on the ward regularly, and/or accompanies them to appointments.
- There may be more than one carer looking after the person, as friends and family members take on different roles.
- The carer may have been identified during the patient’s admission. You could check the patient’s record – the person named as their next-of-kin may also be their carer.

How to identify a carer
- If appropriate, you could ask the person if they have a friend or family member who is supporting them. Remember this can include young people under 18.
- Avoid asking the patient if they have a ‘carer’ or if someone is ‘caring’ for them – many people aren’t familiar with this term and may think it means a paid care worker.
- Patients from black and minority ethnic communities may be unfamiliar with the concept of being a ‘carer’, especially as the term may not exist in their language.
- If the patient does not have someone who could ask how the person is coping.
- Explain that there is support available for people who look after (care for) a relative or friend.
- If you’re not able to find out from the patient if anyone is caring for them, you may need to identify their carer(s) yourself.
- Remember their carer may visit in the evenings due to work or other responsibilities at home.
- Their carer may ask you or other colleagues about the patient’s condition/treatment. They may also ask for advice about looking after them at home.
- If the patient’s family and friends don’t speak English as a first language they may not approach you in this way. You may need to initiate conversations with the help of an interpreter.
The Triangle of Care

The Triangle of Care (ToC) includes key standards and resources to support mental health service providers ensure carers are fully included and supported when the person they care for has an acute mental health episode. Although specifically aimed at mental health services, these standards could apply across a wide range of health and social care settings.

The guide sets out the six key elements (standards) required to achieve better collaboration and partnership with carers in the service user and carer’s journey.

The Key Standards

1. Carers and the essential role they play are identified at first contact or as soon as possible thereafter.
2. Staff are ‘carer aware’ and trained in carer engagement strategies.
3. Policy and practiced protocols re: confidentiality and sharing information are in place.
4. Defined post(s) responsible for carers are in place.
5. A carer introduction to service and staff is available, with a relevant range of information across the care pathway.
6. A range of carer support services are available.

The Triangle of Care is a therapeutic alliance between service user, staff member and carer that promotes safety, supports recovery and sustains wellbeing.
Equal Partners in Care

Equal Partners in Care (EPiC) is the national framework for workforce learning and development related to unpaid carers. It comprises of a set of core principles (below) based on six key outcomes for carers and young carers. Each outcome is linked to the knowledge and skills workers need to work effectively with carers to achieve this outcome.

Core Principles

(click each principle for more details (external links)).

- Identified
- Supported and empowered to manage their caring role
- Enables to have a life outside caring
- Fully engaged in the planning and shaping of services
- Free from disadvantage or discrimination related to their caring role
- Recognised and valued as Equal Partners in Care

There are three levels which are designed to work cumulatively (see below). Everyone who may come into contact with carers in any setting should have at least Level 1 awareness of carers. Those with more regular contact with carers should also have Level 2, while those with a leadership role should also have Level 3. (click image below for more details (external link)).
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**Level 1**
**Carer Aware**
This level is for all workers (including volunteers) who may come into contact with the public and therefore carers. This supports the Carers Strategy vision that ‘it is everyone’s job to identify and support carers.’

**Level 2**
**Caring Together**
This level is for all workers who have regular contact with carers and families, or who have a specific role in carer support.

**Level 3**
**Planning with Carers as Equal Partners**
This level is for those with a leadership role in planning, shaping, delivering or commissioning services. This may include workforce training and supporting staff.

**RESOURCES**

- Triangle of Care resources
- EPiC Practice Guidance
- EPiC eLearning Modules

**Working with young carers**
A young carer is under 18, or 18 and still at school. The average of a young carer is 12 years old, although there are young carers of all ages.

Young carers should be viewed as children and young people first and foremost, and should not take on any inappropriate caring roles. Identifying and involving young carers is an essential part of helping ensure they are properly supported and that inappropriate caring responsibilities are removed and the cared-for person supported in other ways.

Under **Getting it Right for Every Child** all professionals have a responsibility to consider the wellbeing of any child or young person affected by the condition or behaviour of adults using their services.
Involving Carers in Discharge Planning

For young carers it is important to consider whether their caring responsibilities are appropriate to their age and stage of development. It can help to find out:

- How much the young carer understands about the patient’s discharge and what will happen afterwards
- How the patient understands the child or young person’s caring role, and whether there are differences in accounts given by the patient and the young carer
- Whether the young carer might need someone to speak or advocate on their behalf
- Whether there are other children in the family and how they might be affected by the patient’s discharge.
Defined Carer Support Posts
While it is fundamentally important that all staff should be competent in working with carers, this work needs to be coordinated, managed and led.

Anyone with an interest in carers and the issues they face could be appointed Carers Lead. This may be a role taken on by any member of the staff, including administrative staff, or an independent/Third Sector organisation.

- Act as carers main point of contact
- Maintain a carers register
- Source info to provide during hospital stay & on discharge
- Signpost carers to local support services
- Keep colleagues up dated with developments in carer support, notionally and locally

Carers often find it difficult to monitor their relative or friends progress, or to share information, due to the shift system on wards. In addition to a Carer Lead, teams should appoint a member of staff to act as a carer link for each shift or team. This will provide additional continuity in receiving and sharing information, and be a clear point of contact.
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Key Points to Involve Carers

**Hospital admission**
- Provide the person, family, carer or advocate with an opportunity to discuss their care on admission.
- Discuss with patient whether, and how, they would like their carer involved.

**In hospital**
- Keep the carer informed of patient progress, and estimated discharged date.
- Discuss future care needs, including potential for rehabilitation and recovery.

**Step-down care**
- Fully explain the benefits of receiving a short period of Intermediate Care in a more homely setting.
- Encourage carers to be involved in the rehabilitation and recovery process.
- Discuss any additional support the carer may need to continue caring.

**Discharge planning**
- Start planning discharge as soon as possible after admission.
- Fully involve the patient and carer in planning for discharge.
Confidentiality, capacity and consent
More detailed information on working with and discharging adults who lack capacity can be found in the guide *Discharging Adults with Incapacity* (see resources below).

Confidentiality and Consent
The law presumes that all adults have capacity to give or withhold consent to the sharing of their personal information. When seeking consent to share confidential information, remember that:

- Practitioners need to establish whether the patient understands the value of sharing, as well as the risk of not sharing personal information with their carer.
- Discussions about involving carers and sharing information with them should be on-going: sometimes views can change and issues of consent should be regularly reviewed.
- When a patient agrees information can be shared, this agreement does not give carers a general right of access to the patient’s records or to non-relevant information.

It can be difficult if a patient has capacity, refuses to consent to information being shared, and yet needs important support from their carer to remain safe and well. In these cases, it can help to:

- Explore with the patient the reasons for not sharing information.
- Remember that patients might be willing to give limited consent to share certain information.
- Work with the patient to select and negotiate information that could be shared.
- Plan to talk about the issues again, so that obtaining consent to a helpful level of information sharing becomes part of on-going discussions between patient, carers and professionals.

Capacity
It can also be difficult if a patient lacks capacity to consent, and professionals think confidential information needs to be shared with carers. In these cases, the following considerations are important:

- Whether the patient’s lack of capacity is temporary or permanent.
- Whether and how the patient could be encouraged and supported to participate in decisions about disclosure of their personal information.
- The patient’s previously expressed view and preferences.
- The role of anyone with legal authority to make decisions on the patient’s behalf, or who has been appointed to represent the patient.
- The views of people close to the patient including carers.
### Involving Carers in Discharge Planning

#### RESOURCES

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- NICE Quality Standard: Transition between inpatient hospital setting and community or care home setting for adults with social care needs - [https://www.nice.org.uk/guidance/ng27](https://www.nice.org.uk/guidance/ng27)

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- Triangle of Care resources – [https://professionals.carers.org/working-mental-health-carers/triangle-care-mental-health](https://professionals.carers.org/working-mental-health-carers/triangle-care-mental-health)

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- Patients’ Rights (Scotland) Act - [http://www.gov.scot/Topics/Health/Policy/Patients-Rights](http://www.gov.scot/Topics/Health/Policy/Patients-Rights)

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