



Coming out of hospital

A guide for carers

About this guide

This guide provides carers with information on what to expect when a patient is coming out of hospital. Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner.

Making decisions about caring

When a patient leaves hospital a carer can be faced with important decisions and pressures. You may be taking on a caring role for the first time and you don't know what to expect. You may already have been caring, but your caring role may be changing when the patient comes out of hospital. You may be unsure whether you can provide all the help they need. You may also be anxious to get the patient home as soon as possible or feel pressure from friends, family or the patient him/herself.

Whatever the pressures, it is important for you to consider how your new caring situation is likely to affect your life. Is it likely to affect your job? Will it affect your relationships with your partner, children or other family members? Will your own health be put at risk by taking on caring responsibilities because of stress levels or from tasks such as lifting the patient?

Choices and rights

It is your choice whether or not to look after an adult. Just because you are unable to care **for** someone does not mean that you do not care **about** them.

You will need to think about how much care you are able to provide and what help you might need. You have a legal right to have your needs addressed and this is achieved by having a carer's assessment.

Carers' assessments

You have to ask for a carer's assessment from the local social services department (or social work department in Scotland) of the person you are caring for. You have a right to a carer's assessment if you are over 16 and providing regular and substantial care to someone over 18. If the department decides that it is going to provide services to you as a carer it can do so directly or by means of 'direct payments' (see page 3). Here are some of the areas your carer's assessment should consider:

Checklist

- Your own physical and mental health
- Your accommodation and finance
- Your need for respite, leisure and social life
- Wider commitments you have – to family members for instance
- Any need to juggle caring with paid work. You may also have certain legal rights when you are a carer in paid employment. These include the right to take unpaid emergency leave, parental leave to look after a disabled child and the right to request working on a flexible basis.
- The emotional support you need
- Any education or training needs you have
- Specific training for your caring role eg instruction in lifting safely
- Planning for an emergency
- The caring role you want to have in future. Remember that this role is voluntary and your wishes about that should be respected.



The carer's role in the discharge process

Planning for a patient's discharge should take place at the earliest opportunity. You and the patient should be involved at all stages of planning for discharge. Hospital and social care staff should work together to manage all parts of the discharge process. This is to ensure that the patient is suitably cared for after they have left hospital and not at risk of being unable to cope.

Checklist

- You and the patient should expect to be given both spoken and written information, with contact details and any relevant information about future treatment and care. The information should be available in a language suitable for you, large print or Braille.
- A 'discharge co-ordinator' (or ward care co-ordinator) should be available to co-ordinate the planning process and act as a key person for you to contact to find out what the discharge plans are.
- In situations where a patient does not want you to be involved or have information about their care, you should be informed of this and advised of your right to your own assessment.
- If the patient lacks mental capacity you may be able to make certain decisions about health and welfare matters if you have a Lasting Power of Attorney (LPA) dealing with health and welfare matters. If there is no LPA the law requires professionals to act in the patient's 'best interests' and you should be involved in the decision making process.

The discharge procedure

In many cases patients do not need any support from social services or the NHS after discharge. If the patient is thought to have a need for further support from the NHS and/or social services after discharge the procedure is as follows:

Checklist

- An assessment for **NHS continuing care** should be carried out where it appears there may be a need for such care
- The patient and carer should be consulted about whether or not to involve social services

- Social services are then notified assessments are required
- Both patient and carer's assessments are carried out
- A care plan is drawn up setting out what services will be provided
- A financial assessment is carried out to determine any charges for services
- The care plan is implemented

What is the NHS continuing care assessment?

This is an assessment to establish whether the NHS should continue to fund care after discharge from hospital. The care is provided free of charge. To qualify for NHS continuing care a person leaving hospital must have a 'primary health need', a need for nursing or other health services which are not just incidental or ancillary to services which the local authority could be expected to provide. Your view of the patient's needs should be included when the multi disciplinary team assesses eligibility for continuing care. If continuing care is offered, it could be provided in someone's own home or in various types of residential care, such as a residential or nursing home.

PRACTICAL HELP

What type of services might be available?

There are a wide range of care services that can be offered to the patient, depending on their individual needs and circumstances. The following are some of the possibilities:

Intermediate care: is offered where a patient is thought to need extra time to recuperate or additional support after discharge, but is not in need of NHS continuing care. Intermediate care can take place in the patient's own home, a day care facility or in residential care but typically for quite a short period of time and usually no more than six weeks. No charges should be made for intermediate care.

Rehabilitation and recovery services: these are after care services to promote independent living and make it less likely that readmission to hospital is necessary. Those with chronic conditions, such as Parkinson's



disease, as well as those who need rehabilitation after a particular event, such as a stroke, should have longer term rehabilitation services available to them.

Palliative care: this refers to the type of care needed when someone has a health condition which is not expected to be cured by medical treatment. There is a difference between this and a '*terminal illness*' where death is expected to take place within a given period of time. Palliative care will consist of pain relief and other appropriate medical care, as well as providing emotional and practical support. It may take place in a hospice, residential care or in someone's own home. Where the illness is thought to be terminal the individual may be '*fast tracked*' for immediate provision of NHS continuing health care.

Residential care: the patient may be assessed as unable to return to their own home and in need of residential care of some type. Both you and the patient should be offered detailed information and advice, and possibly support such as an advocacy service, when making this type of decision. In most cases the local authority does not have the power to force the patient to go into residential care. Where residential care is refused, the patient does not have the right to stay in the NHS acute ward but the local authority and hospital should work with both of you to explore other options.

There are '*Choice of Accommodation Directions*' which set out how the individual should be allowed to choose their preferred accommodation. This is subject to certain conditions, such as the local authority deciding that the accommodation is suitable and that the cost of them providing this accommodation is not more than they would usually pay to meet those assessed needs.

Warden assisted housing schemes: where there is someone on site to provide assistance where needed, although the level of assistance will vary from scheme to scheme.

Supported Living: this refers to schemes where residents receive some assistance with daily living but are encouraged to be as independent as possible.

Care at home

The following services may also be provided, either as an alternative to the services listed above or in addition to some of them:

Checklist

- Aids and adaptations, eg stair lifts, hand rails. There are grants available for large scale adaptations and minor adaptations (under £1000) should be provided free of charge
- Care workers to provide support, eg help with getting in and out of bed or getting dressed
- Day care facilities for recreation or therapy
- Help with home maintenance, eg home handyman services
- Laundry/incontinence services
- Meals on wheels
- Holidays

Direct payments

Once the services that a patient can receive have been agreed, the patient can choose whether social services arranges those directly or whether the patient would prefer a '*direct payment*' to purchase the services needed themselves.

There are pros and cons to be considered when choosing whether to have a direct payment. For example, where the payment is used to employ a careworker of your own choice it may allow for more flexibility and independence. On the other hand the person receiving the direct payment effectively becomes the employer for legal purposes and has all the responsibility that goes with that role, such as making deductions for tax and national insurance contributions, dealing with holidays, sickness, redundancy etc. In some areas of the country there are organisations that can help with the administration of direct payments.

Charging for services

Residential care

If NHS continuing care has been agreed there will be no cost to the person going into residential care. Where a level of nursing is required (but not full NHS continuing care) the NHS will pay a flat rate contribution towards the cost of care. A decision about full NHS continuing care should be made before any assessment for NHS funded nursing care is made. In other cases, the local authority will carry out a financial assessment to determine whether the resident will need to be '*self funding*' (pay all the costs of care), or pay a contribution towards care.



Care at home

If part of the care provided at home is NHS continuing care (or other NHS services) it will be free of charge. Where other care is provided by social services, most local authorities charge for those services.

Services to carers and charging

You will also be financially assessed for services provided to you. There are rules about the type of income and capital that can be taken into account. Only your own income and capital (rather than that of the person for whom you care) is relevant and any paid earnings you have can be disregarded.

Direct payments

Charges may be applied whether the service is delivered directly by social services or by means of a direct payment.

DISCHARGE DAY

You and the person you care for should expect the following type of arrangements to be made for the day of discharge:

Checklist

- Appropriate transport should be organised if it is required
- You should both be given copies of your care plans
- A discharge letter should be sent to the patient's GP within 24 hours
- You should be notified of any follow up arrangements, such as hospital appointments as well as details of who to contact if you have any difficulties
- Medication and any equipment needed at home should be dispensed to the patient, as well as instructions and information about its use
- Any necessary domiciliary services should be put in place to start on the day of discharge
- A discharge 'lounge' (or similar space) should be available for use in the hospital while waiting for transport, medication etc.

COMPLAINTS

Sometimes hospital discharge may not be carried out satisfactorily. For example, the patient may be left without vital support or not given the right advice. At the end of this fact sheet is a list of legislation and guidance which may be useful in challenging decisions. However you do not need to refer to this – what matters is that you explain as clearly as possible what it is that went wrong and what you wanted instead. There are different ways of resolving a dispute, depending on what has gone wrong:

Informal complaint

You may want to make an informal complaint to start with by speaking to the discharge co-ordinator or social worker immediately involved with the arrangements. In some cases you may feel this is sufficient to resolve the matter.

If an informal approach does not resolve matters you could use the formal complaints systems listed below.

Using the NHS complaints system

Either the patient or you can make a complaint about how you have been treated or the care provided. That complaint should normally be made within six months of the incident in question (in some cases a longer period of time would be acceptable).

Assistance in making an NHS complaint

The Patient Advice and Liaison Service (PALS) will help you make your complaint and can try to resolve matters at an early stage. They will also be able to put you in touch with your local Independent Complaints Advocacy Service (ICAS) if the complaint needs to go forward. To find your nearest PALS you can telephone NHS Direct on 0845 4647. There are several stages to the complaints process.

Stage 1. The complaint is made verbally or in writing to the 'complaints manager' who will acknowledge it in writing. The complaints manager will then investigate and must give a written response, normally within 20 working days of the date on which the complaint was made.

Stage 2. If the complaint is not resolved to your satisfaction an independent review can take place within two months of receiving the Stage 1 response. The Healthcare Commission (in England) or Independent



Review Secretariat (in Wales) will appoint a case manager to undertake an initial review. The outcome at this stage may include, for example, a recommendation that no further action be taken, referral to a panel hearing or referral to another body such as the Health Service Ombudsman. The complaint may also be referred back to the NHS body with recommendations for further action.

A complaint to the Health Service Ombudsman

If you are unhappy with the results of a panel hearing you could then complain to the Health Service Ombudsman.

If your dispute has to do with assessment for continuing NHS health care

If this is the subject of the complaint, different procedures apply. If you are not satisfied with the outcome of your complaint about the continuing care assessment you can apply to a Strategic Health Authority (SHA) panel for a review (Local Health Board (LHB) in Wales).

Complaints about social services

If your complaint has to do with social services you should use the local authority's statutory complaints procedure. Again, there are various stages to the procedure. If your complaint is not resolved you may be able to take it to the Local Government Ombudsman.

Assistance in making a complaint to social services

You may be able to get assistance with making a complaint to social services from a local carers' centre, support group or advocacy service.

Not sure whether to complain to social services or the NHS?

If you started by complaining to the NHS but it appears to the NHS complaints manager that your complaint (or part of it) should be made to the local authority, you should be informed and have your right to use the social services complaints procedure explained to you.

There are different ombudsmen for health (Health Service Ombudsman) and social services (Local Government Ombudsman) but they have the power to carry out joint investigations.

Judicial review

In some cases an application for Judicial Review of a social services or NHS decision by the High Court may be possible. Acting promptly in this situation is extremely important and you should seek advice as soon as possible.

BENEFIT CLAIMS

It is important to notify the relevant benefit office that the person you care for is going into hospital as this may affect their benefit as well as your own benefit. So when the patient is ready to be discharged you will need to inform the office dealing with the particular benefit to make sure that payments restart.

You may of course also be involved in making fresh claims for benefit after they have been discharged from hospital. Bear the following points in mind –

- Disability Living Allowance or Attendance Allowance may stop if the patient has been in hospital for more than 28 days (84 days if the patient is a child) but the mobility component of Disability Living Allowance can continue in some cases. You should also note that sometimes different periods of stay in hospital can be linked together and benefit will stop.
- Your entitlement to Carer's Allowance will stop once the person you care for no longer receives Disability Living Allowance or Attendance Allowance.
- Other benefits may be affected after a patient has been in hospital for 28 days, and may be further affected or stop completely after they have been a patient for 52 weeks.

The rules relating to benefits are complex – for further advice and information contact CarersLine (see below) or your local Citizens Advice Bureau.

FOR FURTHER HELP

For advice on any of the above matters, and to be signposted to local services please contact Carers UK's advice line CarersLine on 0808 808 7777.

The line is available on Wednesdays and Thursdays from 10am to 12 noon and 2 to 4pm.

Information is also available on our website:
www.carersuk.org



FURTHER ADVICE AND INFORMATION

Older people, residential care, charging and NHS continuing care

Age Concern www.ageconcern.org.uk 0800 009966
Counsel and Care www.counselandcare.org.uk
0845 300 7585

Direct payments and independent living

National Centre for Independent Living
www.ncil.org.uk 020 7587 1663

Mental capacity and Power of Attorney

The Office of the Public Guardian
www.publicguardian.gov.uk 0845 330 2900

Mental health

MIND www.mind.org.uk 0845 766 0163

Learning disability

Mencap www.mencap.org.uk 0808 808 1111

Legislation and guidance

The Community Care (Delayed Discharges) Act 2003
Community Care (Delayed Discharges) Act 2003 – Guidance for Implementation
Discharge from hospital: pathway, process and practice
Hospital Discharge Planning Guidance (National Assembly for Wales Circular 17/2005)
Scottish Executive Guidance on hospital discharge SWSG 10/1998
NHS Continuing Healthcare (Responsibilities) Directions 2007
National Service Framework for Older People 2001
National Service Framework for Mental Health 1999
'A positive outlook – a good practice toolkit to improve discharge from inpatient mental health care' 2007
National Service Framework for Long term Conditions 2005
Valuing People: A New Strategy for Learning Disability for the 21st Century 2001
Guidance to the Choice of Accommodation Directions – LAC (2004) 20
Charging for Residential Accommodation Guide (CRAG)
Fairer Charging Policies for Home Care and other Non-Residential Social Services 2001

Disclaimer: The information in this leaflet only applies to England and Wales and is for guidance only. It is not an authoritative statement of the law. The information is correct as of February 2008.

CARERS UK

the voice of carers

Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner. Carers give so much to society yet as a consequence of caring, they experience ill health, poverty and discrimination.

Carers UK is an organisation of carers fighting to end this injustice. We will not stop until people recognise the true value of carers' contribution to society and carers get the practical, financial and emotional support they need.

Carers UK is here to improve carers' lives.

- We campaign for the changes that make a real difference to carers' lives.
- We make sure carers understand their rights and know how to get support.
- We gather hard evidence about what needs to change.
- We mobilise carers and supporters to influence decision-makers.
- We transform the understanding of caring so that carers are valued and not discriminated against.

JOIN CARERS UK TODAY

Add your voice by joining Carers UK which will strengthen our campaigning power to improve the lives of the UK's six million carers. You will benefit by receiving our free magazine, *Caring*, full of the latest information, practical tips and carers' stories. We offer 'pay as much as you can', including free membership for carers on a low income.

www.carersuk.org

info@carersuk.org

Membership line: 020 7566 7602

CarersLine: 0808 808 7777 (open Wednesday and Thursday 10am-12pm and 2pm-4pm)

Switchboard: 020 7490 8818

Fax: 020 7490 8824

CARERS UK, CAN Mezzanine, 32-36 Loman Street, Southwark, London SE1 0EE

Carers UK is registered in England and Wales as a company limited by guarantee number 864097. Registered charity number: 246329

© Carers UK February 2008

Publication code EW1012

This publication has been made possible thanks to the kind support of the Beatrice Laing Trust.