

Coming out of hospital



Deciding to care or continue caring for someone who is coming out of hospital and who can no longer care for themselves in the same way as before can be difficult. This factsheet explains your rights as a carer, the steps that should be followed and what to do if things go wrong. It applies to people living in England.

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If the person you care for is in hospital

If the person you care for is in hospital you may be faced with important decisions. You may be considering taking on this caring role for the first time and don't know what to expect. Or you may have already been caring for the person, but their needs have now increased or changed.

One important thing to remember is that it is your choice whether or not to take on a caring role. Think about the type and amount of support you are able to provide and what help you might need. For example, you may be able to help with shopping and meals but feel that you would both like someone else to help with personal care. It is important for you to consider how your caring role is likely to affect your life and wellbeing.

An outline of the discharge procedure

Each hospital will have its own discharge policy based on guidance from the Government. You can request a copy of the hospital's discharge policy from the ward manager or from the Patient Advice and Liaison Service (PALS) department of the hospital.

Discharge planning starts as soon as the person you care for is admitted to hospital. It is important to let the hospital staff know as early as possible if you are a carer or thinking of taking on the role. A discharge coordinator (or ward care coordinator) should be available to coordinate the planning process. They will act as a key person for you to contact to find out what the discharge plans are.

Should I, as a carer, be involved in the discharge procedure?

The hospital discharge policy should emphasise the importance of involving you and the person you care for at all stages of discharge planning, so long as the person you care for consents to this. Hospital wards can sometimes seem like busy or intimidating places and you may feel pressure from the hospital to get the person you care for home as soon as possible. The person you care for may be anxious to come home. However, it is important that you feel your views have been taken into consideration and that the person you care for is not being discharged before necessary support has been put in place. In situations where the person you care for does not want you to be involved or be given information about their care, you should be informed of this.

If the person you care for 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). If there is no LPA the law requires professionals to act in the 'best interests' of the person you care for and you should be involved in this decision making process.

▶▶ **Note:** For more information on mental capacity visit carersuk.org/mental-capacity or contact the Carers UK Helpline – see final page for contact details.

What should happen before the person I care for is discharged?

When the person you care for is nearing their expected date of discharge the following steps should be taken:

- ▶ An assessment should be carried out to see if they are medically fit to be discharged.
- ▶ A discharge assessment should be carried out to see if they need support once discharged (see page 4).
- ▶ A carer's assessment should be carried out (or at least arranged), to see whether you as a carer need support once the person you care for is discharged (see page 7).
- ▶ A written care and support plan should be given to the person you care for (and a support plan for yourself if you have had your own carer's assessment), which outlines the support required and how this will be provided.
- ▶ The support outlined in the care and support plan (for the person being cared for) and the support plan (for you) should be put in place.

What should happen on the day the person I care for is discharged?

On the day of discharge you and the person you care for should expect to be given both verbal and written information, with details of any services involved and information about future treatment and care. The information should be available in a language and format suitable for you. It is common that people do not remember or understand all the information they are given so don't be afraid to ask for it to be repeated or explained in a different way.

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

- appropriate transport should be organised if it is required
- you should both be given copies of the care and support plan (for the person being cared for) and the support plan (for you)
- a discharge letter should be sent to the GP of the person you care for within 24 hours
- medication and any equipment needed at home should be dispensed to the person you care for, as well as instructions and information about its use
- any necessary support 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.

The discharge assessment

The discharge assessment, which is to see if the person you care for needs support once discharged, might be carried out by a multidisciplinary team of health or social care professionals. This is to avoid multiple assessments being carried out.

This discharge assessment should look to see whether the person you care for is eligible for any intermediate or reablement care, NHS continuing healthcare or NHS funded nursing care, other NHS services and/or community care services from the local authority.

Intermediate or reablement care

Intermediate care is a short term package of care which is provided with the aim of assisting the person you care for to maintain or regain the ability to live independently at home. Government guidance states that intermediate care should be available to all adults over the age of 18 who might need it and certain young disabled people while managing their transition to adulthood.

Intermediate care could include any of the following:

- crisis response services providing short term care

- home-based care services provided by health professionals such as nurses and therapists
- bed-based care away from home such as in a community hospital
- reablement.

Reablement is a particular type of intermediate care which has a stronger focus on helping the person you care for to live independently. It is generally provided by local authorities.

Before the intermediate care or reablement ends, there should be another assessment to determine whether the person you care for has ongoing needs for care and support (if this has not already been decided).

Intermediate and reablement care should be provided free of charge for up to six weeks (although this can be longer in some circumstances). After the six weeks if there are ongoing support needs which are being met by the NHS, these should be free of charge. If there are ongoing support needs which are being met by the local authority, they can charge for such services.

NHS continuing healthcare or NHS funded nursing care

NHS continuing healthcare is a package of care for those who are 18 or over who have a 'primary health need' that is arranged and funded by the NHS. This package of care can be provided in the home of the person you care for, in a care home, or via a personal budget.

If it seems like the person you care for might be eligible for NHS continuing healthcare an assessment should be carried out for this. Generally there is an initial checklist assessment which determines whether the person you care for will be told they don't meet the criteria for a full assessment and are therefore not eligible, or whether they will have a full assessment of eligibility. Be aware that the eligibility criteria are very tight and most people with ongoing care needs won't qualify.

Around 60,000 people in England are currently in receipt of NHS continuing healthcare. NHS funded nursing care is available if the person you care for is 18 or over and is not eligible for NHS continuing healthcare, but they are assessed as requiring nursing care in a care home that is registered to provide nursing care. This means that the NHS will pay a contribution towards the cost of their registered nursing care.

▶▶ **Note:** NHS continuing care is the alternative provision for children under 18. It is different to adult NHS continuing healthcare in that the whole package of care is not normally arranged and funded by the NHS. Rather, a holistic approach is adopted when assessing children for continuing care that incorporates social services and education departments in addition to the NHS, which may lead to joint funding arrangements, depending on the child's assessed needs.

Other NHS services

Palliative care can be provided free on the NHS and is for people who have a health condition which is not expected to be cured by medical treatment. Palliative care can consist of pain relief and other appropriate medical care, as well as providing emotional and practical support. It can take place in a hospice, residential care or the person's own home. Medical equipment and incontinence products can be provided free on the NHS if the person you care for is assessed as needing such items.

Community care services from the local authority

Most people being discharged from hospital won't need or be eligible for NHS continuing healthcare. Instead they can have an assessment from the local authority, to determine whether they are eligible for any support. Support could include things such as equipment or adaptations to the home, a care worker to help provide personal care etc.

The hospital should give an assessment notice to the local authority so that they can carry this out as part of the discharge assessment. For those who are 18 or over this will be called a needs assessment and for a child (under 18) this will be called a Children Act assessment.

If the person you care for is assessed as needing support from the local authority, they will carry out a financial assessment to determine whether, and if so how much, the person will need to contribute towards the cost of any support provided.

The carer's assessment

As a carer you can have an assessment from the local authority, to determine whether you are eligible for any support. Support could include services provided directly to you, or services provided to the person you care for, which in turn would help you in your caring role.

There are various different types of assessments depending on whether you are an adult yourself, and whether the person you are caring for is an adult.

▶▶ **Note:** For more information on the different types of assessments available visit, carersuk.org/assessments or contact our Helpline (contact details on final page).

If you are assessed as needing support from the local authority, the local authority might carry out a financial assessment to determine whether, and if so how much, you will need to contribute towards the cost of any support provided. However, it is hoped that a lot of local authorities will not charge carers for support provided to them. If the support is provided to the person you are caring for, you as a carer cannot be charged.

Discharge from a mental health facility

If the person you care for is in a mental health facility, then they may be there as a voluntary in-patient (which means they can choose to leave if they want), or they may be there because they are detained under the Mental Health Act. There are special rules that apply to discharge from hospital following a section under the Mental Health Act – see page 8. Before the person you care for is discharged from a mental health facility, there should be a meeting to assess what support or care services may be needed once they are back in a community setting. In addition to having a needs assessment for community care services (see page 6), the person you care for may receive some of the mental health specific support outlined below. As a carer you should be involved in this process if the person you care for consents to this.

Community Mental Health Teams

If the person you care for is being discharged from a mental health facility, they may be referred to a Community Mental Health Team (CMHT) which is made up of different mental health professionals from both health and social care. There are also specialist CMHTs that the person you care for may be referred to, depending on their assessed mental health needs at the point of discharge.

If the person you care for is under 18, then they may be referred to Child and Adolescent Mental Health Services (CAMHS). If the person you care for is over 65 then they may be referred to an Older People's CMHT.

The Care Programme Approach

If the person you care for is assessed as having complex needs requiring long-term support at the point of discharge, then they may be placed under the Care Programme Approach (CPA). The CPA is a national framework that CMHT's work within to coordinate the care and support services received by patients with complex mental health needs. If the person you care for qualifies for the CPA, some of the things they should expect to receive include:

- a full assessment of their health and social care needs
- a care plan that is regularly reviewed
- a Care Coordinator who is responsible for making sure the care plan gets implemented and meets assessed needs.

▶▶ **Note:** As a carer you should be involved in the Care Programme Approach (CPA) meetings if the person you care for consents to this.

Discharge from the Mental Health Act

If the person you care for is detained under a section of the Mental Health Act, there are certain restrictions on how they can be discharged from section. The different ways this can be done can include where:

- the section runs out and is not renewed

- the professional in charge of the person you care for (the Responsible Clinician) discharges them
- the nearest relative of the person you care for (as defined in the Mental Health Act) discharges them (although the Responsible Clinician can override this)
- the Mental Health Act Managers discharge them
- a tribunal discharges them.

Mental Health Act guidance suggests that the person you care for should not be discharged from section or from hospital by their Responsible Clinician until arrangements have been put in place for care and support in the community. In terms of what type of care this might include, in most cases the person you care for will receive specialist support from an appropriate CMHT under the CPA.

If the person you care for has been detained in hospital under section 3, 37, 45A, 47 or 48 of the Mental Health Act, then they are entitled to free aftercare services under section 117 of the Act.

The free aftercare is funded by the NHS and local authority in the area where the person you cared for lived before they were admitted to hospital. Aftercare services will be based on the health and social care needs identified in the care plan of the person you care for. As a carer you should be involved in the care plan if the person you care for consents to this.

▶▶ **Note:** Discharge from the Mental Health Act is a complicated area and therefore if this applies to the person you care for, you may need to seek further advice from a specialist mental health charity (see contacts section on pages 14-15).

Other important things to think about if the person you care for is in hospital

Benefit claims

It is important to notify the relevant benefit office that the person you care for is going or has gone into hospital, as this may affect their benefits as well as your own.

If the person you care for was 18+ when they went into hospital then some benefits such as Disability Living Allowance (DLA), Personal Independence Payment (PIP) or Attendance Allowance will stop if the person you care for has been in hospital for more than 28 days. If the person you care for was under 18 when they went into hospital then their DLA or PIP can continue to be paid for the whole time they are there.

Stays in hospital or a care home which are separated by 28 days or less are added together when working out when the benefit should stop (called the 'linking rules').

If the Disability Living Allowance, Personal Independence Payment or Attendance Allowance of the person you care for stops, your Carer's Allowance will also stop.

When the person you care for is ready to be discharged, inform the office dealing with the particular benefit to make sure that payments restart. The person you care for may also be eligible for benefits at an increased rate if their care needs have changed.

▶▶ Note: The rules relating to benefits are complex. For further advice and information contact the Carers UK Helpline – see final page for contact details.

Help at work

If you are in paid work you may need to make some adjustments if the person you care for goes into hospital and/or when they come out of hospital. This could be anything from needing to make regular phone calls

to check on them, through to taking off an extended period of leave. Most working carers have the following rights:

- the right to request flexible working
- the right to time off in emergencies
- the right to not be discriminated against or harassed under the Equality Act.

▶▶ **Note:** For more information on your rights in work visit carersuk.org/work or contact the Carers UK Helpline – see final page for contact details.

Complaints

Unfortunately, there may be times when you need to make a complaint. When making a complaint, it is important to explain as clearly as possible what went wrong, and what you would like to happen instead.

Complaints about the NHS

If you, or the person you are looking after, are unhappy with the discharge procedure, with the way you have been treated by the NHS or with an NHS service, you can make a complaint about this. To start with you may want to make an informal complaint by speaking to the person responsible for the issue, which may be enough to resolve the matter.

If the informal complaint does not resolve the matter, you can use the two stage formal complaints procedure outlined below. You should make your complaint as soon as possible, and generally within 12 months of the event you are complaining about.

First stage complaint – local resolution

Local resolution: Raise your concern with the service provider (such as the hospital) or the body which commissions the service (such as the clinical commissioning group). You can ask for a copy of their complaints procedure which will give further information. Your complaint can be in writing or you can complain verbally.

Second stage complaint – Parliamentary and Health Service Ombudsman

If you are still not happy you can take the matter to the Parliamentary and Health Service Ombudsman, who is independent of the NHS. Visit ombudsman.org.uk or telephone **0345 015 4033**.

For more information on making an NHS complaint, you could contact: The Patient Advice and Liaison Service (PALS), who provide a confidential service that is designed to help patients get the most from the NHS – visit nhs.uk/common-health-questions/nhs-services-and-treatments/what-is-pals-patient-advice-and-liaison-service

Healthwatch, who provide information and advice making a complaint about the NHS – visit healthwatch.co.uk or telephone **03000 683 000**.

▶▶ Note: If you want to make a complaint about NHS continuing healthcare the process can differ – visit beaconchc.co.uk/how-itworks/dispute-resolution.

Complaints about the local authority

If you, or the person you are looking after, are unhappy with the way an assessment was carried out, with the way you have been treated by the local authority or with a local authority service, you can make a complaint about this.

To start with you may want to make an informal complaint by speaking to the person responsible for the issue, which may be enough to resolve the matter.

If the informal complaint does not resolve the matter, you can use the two stage formal complaints procedure outlined below. You should make your complaint as soon as possible, and generally within 12 months of the event you are complaining about.

First stage complaint – local resolution

Raise your concern with the local authority. You can ask for a copy of their complaints procedure which will give further information. Your complaint can be in writing or you can complain verbally.

Second stage complaint – Local Government Ombudsman

If you are still not happy you can take the matter to the Local Government Ombudsman, who is independent of the local authority. Visit lgo.org.uk or telephone **0300 061 0614**. You may be able to get help with making a complaint to the local authority from a local advice centre – visit advice.local.uk.

Judicial review

You may be able to take legal action to ask a court to review a decision made by the NHS or a local authority. This is called judicial review. An application for judicial review must be made without delay, and within a maximum period of three months. You will need specialist legal advice if you want to apply for judicial review – visit find-legal-advice.justice.gov.uk. The Law Society can help you find a solicitor. Visit solicitors.lawsociety.org.uk or telephone **0207 320 5650**.

▶▶ Note: For more information on making a complaint visit carersuk.org/making-complaints

Further help

Our website contains a wealth of useful information on the financial and practical matters related to caring - visit [carersuk.org](https://www.carersuk.org) You can find details of your local carers organisation on our website at [carersuk.org/local-support](https://www.carersuk.org/local-support)

For information and advice contact the Carers UK Helpline on **0808 808 7777** open Monday and Tuesday 10am - 4pm or email advice@carersuk.org

Other organisations

Advocacy and advice services

Citizens Advice - Get advice from your local Citizens Advice.

w: citizensadvice.org.uk

POWhER - A charity that provides information, advocacy and advice services across England

w: pohwer.net | **t:** 0300 456 2370

Autism

The National Autistic Society

w: autism.org.uk | **t:** 0808 800 4104

Dementia

Alzheimer's Society

w: alzheimers.org.uk | **t:** 0300 222 1122

Direct payments and independent living

Disability Rights UK - personal budget helpline

w: disabilityrightsuk.org | **t:** 0330 995 0404

Learning disabilities

Mencap

w: mencap.org.uk | **t:** 0808 808 1111

Mental health

MIND

w: mind.org.uk | **t:** 0300 123 3393

Rethink

w: rethink.org | **t:** 0300 5000 927

Young Minds

w: youngminds.org.uk | **t:** Parents helpline: 0808 802 5544

Older people, residential care, charging and NHS Continuing Healthcare

Age UK


w: ageuk.org.uk | **t:** 0800 055 6112

This factsheet is designed to provide helpful information and advice. It is not an authoritative statement of the law. We work to ensure that our factsheets are accurate and up to date, but information about benefits and community care is subject to change over time. We would recommend contacting the Carers UK Helpline or visiting our website for the latest information.

Give us your feedback on this factsheet by emailing your comments to info@carersuk.org
This factsheet was updated in November 2018. Next review due April 2020.

Carers UK Helpline

For expert information and advice about caring.

 **0808 808 7777**
(Monday – Tuesday 10am-4pm)

 advice@carersuk.org

Carers UK

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020 7378 4999
info@carersuk.org

Carers Wales

029 2081 1370
info@carerswales.org

Carers Scotland

info@carerscotland.org

Carers Northern Ireland

028 9043 9843
info@carersni.org

However caring affects you, we're here

Caring will affect us all at some point in our lives.

With your help, we can be there for the 6,000 people who start looking after someone each day.

We're the UK's only national membership charity for carers: join us for free at carersuk.org/join

We're both a support network and a movement for change.

Visit us at our website to join us, help us or access more resources:

carersuk.org

**This information can be requested
in large print or as a text file.**