



Action for Carers CARERS' HOSPITAL GUIDE

A practical guide to all the support you're entitled to as a unpaid carer when the person you care for is admitted to hospital



Using this Guide

Whether you began caring gradually or your life changed overnight, new caring responsibilities bring new challenges, and you will need support. This is especially true when the person you care for is attending, staying in, and particularly being discharged from, hospital.

The guide outlines issues you may need to consider and questions you might want to ask, as well as the support that is available, and details of YOUR rights as a carer, especially around hospital discharge.

We hope it helps you ensure that you and the person you care for have as smooth-as-possible hospital experiences.

And don't forget, we're here to help, with hospital matters, or any issues related to being an unpaid carer.

Please call us, Action for Carers, on **0303 040 1234**,
(text 07723 486730), or email **CarerSupport@actionforcarers.org.uk**
for information and support.



Charity Action for Carers is commissioned by Surrey County Council and the NHS in Surrey to provide support and information to carers.

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Having the person you care for in hospital can be a difficult and stressful experience

Our Hospital Carer Support Advisors are there to help. We have staff at the following hospitals: East Surrey, Epsom, the Royal Surrey County and Ashford and St Peter's.

Wide-ranging support

Our Hospital Carer Support Advisors work closely with hospital staff to identify carers and to support you whilst your loved ones are in hospital.

- They can help bridge communication gaps between you as the carer and hospital staff, including advocacy when appropriate.
- They can offer you advice and information as well as provide emotional support.
- They can signpost carers and their loved ones to support from other organisations.
- They can guide carers through the hospital discharge process.
- They can refer you back to our Carer Support Advisors, once back in the community.

If you need support whilst the person you care for is in hospital or need help with any hospital related issues then please give us a call so we can put you in touch for support.

Feel free to contact the Advisors directly (see opposite), or call ACS on 0303 040 1234 or email CarerSupport@actionforcarers.org.uk



Meet the ACS Hospital Carer Support Advisors



East Surrey Hospital

Katie Davey

Monday to Friday

07989 402663

Katie.Davey@actionforcarers.org.uk



Epsom General Hospital

Michele Moore

Mondays, Wednesdays, Fridays

07736 561978

Michele.Moore@actionforcarers.org.uk

and

Tamzin Ede

(Team manager) Thursdays

07736 561976

Tamzin.Ede@actionforcarers.org.uk



Royal Surrey County Hospital

Naheeda Majid

Monday to Friday

07850 515457

Naheeda.majid@actionforcarers.org.uk



Ashford and St Peter's Hospital

Sam Caine

Monday to Friday

07989 402764

Sam.Caine@actionforcarers.org.uk

What support does Action for Carers provide?

Carer Helpline

We are here for when you need us.

If it matters to you, it matters to us. Carer Helpline Advisors are here during the week to speak to you and provide information, advice, support, or just to listen.

Please call us: 0303 040 1234, CarerSupport@actionforcarers.org.uk

Individual support from a Carer Support Advisor:

- Support by phone, face to face, online or in one of our Hubs
- Help with filling out forms/paperwork
- Guidance on practical and financial matters, as well as on benefits
- Emotional support
- Information about local resources and organisations
- Referrals for further support

Wellbeing events and training workshops

Our free events are both online and in person across Surrey.

Newsletters and emails

Consent to us sending you our newsletter and regular email to keep you up-to-date with the latest carer news, information and events.

Moving and Handling support

As a carer, your role may include helping someone move about.

We can put you in touch with our Moving and Handling service which provides safe solutions for carers who carry out moving and handling as part of their role.

The team offer information, advice, training and support to help carers prevent potential injury to themselves or the person they care for – adults and children. Whether it's simple tips, or discussing more specialised equipment that will help, our team can advise.

Young carer support

We can refer to our service for carers under 18, Surrey Young Carers.

Before going to hospital

When the person you care for is about to be admitted, or has arrived in hospital, here's a few things to think about.

Let's be honest no one wants to stay overnight in hospital let alone longer, but sometimes this is necessary for our loved ones. Here are a few things that might make their stay a little more comfortable.

- An overnight bag to include items such as toothbrush, toothpaste, wet wipes, flannel, towel, hairbrush, hearing aid, glasses etc.
- Sanitary items / incontinence pads (the hospital will have these, but they are a generic one size fits all, which isn't always the most comfy).
- Their own clean clothes – including dressing gown/slippers and something suitable for discharge.
- Snacks or additional drinks (depending on the hospital's guidance).
- Things to do – jigsaw puzzles, books to read, puzzles, sudokus, etc.

Complete a 'This is Me' or 'All about Me' form

Surrey Hospitals use a 'This is Me' form and we have our own version 'All about Me' that we can send you, just ask. Both give information on the person you care for's preferences, such as how they communicate, things that cause them distress, and foods they like. You can leave it with the hospital team to help them care for your loved one.

Twiddlemuffs

If the person you care for has dementia or autism, we have Twiddlemuffs available. These are knitted muffs with different textures and items attached for fiddling with, which can help sooth people.

BEFORE any hospital trip happens

We have a comprehensive ***Emergency Planning Form***, which lists everything someone might need to know about caring for your loved one, should *you* ever not be able to. You can request this from us, or download from our website. Having this completed, and given to relatives, friends, professionals, can give you great peace of mind.

Please don't forget to update these forms when things change!

All about Carer Passports

Each hospital offers their own version of a Carer Passport, these can be obtained from the ward your cared for is admitted to.

A Carer Passport shows the hospital you are a carer and gives you additional help, and sometimes discounts.

Getting a Passport

Generally, it will be a nurse in charge of the ward your cared for person is on, who will issue them, as they come with a 'dynamic risk assessment' – this means an agreement between you and the ward about what care, and how much care, is right for you to provide your loved one while they are in hospital.

The care required by the person you care for might change during their stay in hospital dependent on their condition, so any change to the type of care or how much care you provide, should also be agreed with the nurse in charge.

What the Passport can do

The Passport can also provide discounted car parking and discount on some food outlets within the hospital, as well as out of hours visiting by prior agreement.

Your contact information

Another point to check is that the hospital has you listed as the carer (and next of kin if this is appropriate) on their records, and that your contact details are correct. We advise that you request this at this stage, so that you are included in conversations around discharge planning.

You may want to check too with individual health or social care professionals involved in your loved ones care, that they too are aware of your caring role and have the right contact details.

During the hospital stay: hospital staff

Who's involved in hospital care?

The Multidisciplinary Team will be the main team of clinicians involved in the care of the person you are caring for whilst they are in hospital. The Social Care Team and Discharge Teams will be part of the process. They may have different team names in different hospitals.

Below is some space to keep a note of names of everyone you speak to as this can be confusing due to so many staff contacting you.

Staff name	Team	Contact details	Notes

When the person you care for is not able to make decisions for themselves

Understanding mental capacity

Mental capacity means someone's ability to understand information and make decisions about their life, as well as communicate these decisions. Capacity can vary, depending on what sort of decision has to be made, and when.

When someone is 'lacking capacity'

Someone's lack of capacity can be a temporary issue, or permanent. A permanent lack of capacity would apply in situations like a learning disability or dementia. A temporary, or short-term lack of capacity might be for example because someone is experiencing temporary confusion because of medications, or if the person is unconscious.

Capacity and hospital care

If the person you care for lacks capacity to make decisions about treatment and care and has registered a LPA (Lasting Power of Attorney) for health and wellbeing, and you as the carer are an LPA Executor, then staff should fully involve you, so you can make decisions on their behalf.

If you are not the registered executor, staff must make a 'best interests' decision on the person's behalf, and should consult with you as a carer before doing this. Staff should give you information at every step of this process.

Questions about capacity

If you've any questions about capacity and what it means, or want to find out more about LPAs, please get in touch with a Hospital Carer Support Advisor, or contact our Helpline who can put you in touch with them.

Other issues for carers to consider

Benefits

An extended stay in hospital can impact benefits. It's important to inform the benefit office should the person you care for be admitted.

Some of the benefits that may be impacted are Disability Living Allowance (DLA), Personal Independence Payment (PIP) or Attendance Allowance. If the person receiving these allowances is in hospital for over 28 days and aged 18 or over, the benefit payment will stop.

If you receive Carers Allowance and the person you care for has their benefit stopped, your Carers Allowance will also stop.

Stays in hospital or a care home, that are separated by 28 days or fewer, are added together for the purpose of working out when the benefits should stop, this is often referred to as the 'linking rules'.

You will need to notify the benefits office again once they leave hospital, for payments to be restarted. You may also find that the person you care for may be eligible for benefits at an increased rate if their care needs have changed.

Balancing caring and employment

If you are employed, you may need to speak with your employers to request some adjustments whilst the person you care for is in hospital and on their discharge. This could include, needing to make or receive regular phone calls to check in on them, to needing to take extended leave at short notice. Most working carers have the following rights:

- The right to request flexible working.
- The right to time off in emergencies.
- The right to one weeks unpaid Carers Leave. This is available to some employees currently, and the Carers Leave Act (2023) will make it available to all – at a date in 2024, not yet published. Do also check your employers policies as some offer *paid* Carers Leave.
- The Right to not be discriminated against under the Equality Act.

Preparing for discharge from hospital

Each hospital inpatient stay will be different, and some people will leave hospital with little or no change in their baseline health, compared with before admission, while others may see a decline.

Hospital staff will consider the expected ability for improvements in someone's baseline health as they approach a suitable discharge pathway. Your discharge should be based on individual needs and circumstances at the time.

Hospital discharge policy

Each hospital has their own specific discharge policy based around guidance from government. You can request a copy of the hospital's discharge policy from The Patient Advice and Liaison Service (PALS) or from the ward manager.

Discharge planning actually starts from the moment someone is admitted to hospital. It's important to identify yourself as a carer to hospital staff and ask to be included in the discharge planning process.

As part of the discharge process, you should be asked as a carer if you are **WILLING AND ABLE** to care for your loved one. Please give this some thought, are there areas of care you are happy to provide and other areas that you are not able to provide? This is a great opportunity to communicate this with professionals.

The discharge process identifies four types of patients. Those who:

1. Need minimal help on discharge.
2. Would benefit from short term support to recover further at home, before assessing their long-term care needs.
3. Would benefit from short term support to recover further in a residential setting, before assessing their long-term needs.
4. Are unlikely to benefit from short term support and need ongoing nursing care, most likely in a nursing/care home.

The discharge teams have multiple ways to provide support.

Leaving hospital: preparing for discharge

Some hospitals have virtual wards available for patients to finish their treatment at home, some may consider inpatient rehab placements and others reablement packages at home.

Please note, what was a suitable discharge option following a previous admission, may not be suitable in future circumstances.

Minimal support on discharge

Ward staff manage the discharge of patients needing only minimal help, for example with transport home or someone to switch on heating. They can provide information on organisations who can help, for a few weeks, with tasks such as shopping.

Support to recover further at home or in a residential setting

The person you care for may have potential for further recovery when their need for hospital care finishes. They may benefit from support to maximise their recovery before staff assess their long-term needs. If so, staff will discuss with you and the person you care for what this might mean and appoint a case worker.

The case worker will work to arrange the recommended discharge, this may be home with the support of a package of care, visits from the district nursing team or hospitals virtual wards. A short-term placement on a rehab ward or in a care home may also be considered. This additional support is expected to be short term to help them further recover.

Staff are expected to assess their longer-term care needs within four weeks, this could be extended to six weeks. If the person you care for is unlikely to benefit from further support professionals will discuss their long-term needs with them and you and any other family as appropriate.

If the person you care for's needs are too great to return home, they may be discharged from hospital to a residential setting such as a care/nursing home. If there is a need for a higher level of care, then a social worker will be appointed to arrange discharge to a care/nursing home along with a full needs assessment, so you and the person you care for can review all the options and move to a long-term care/nursing home.

What should happen during and post discharge?

What to ask – and check – at discharge

Before, and after discharge, a number of things should happen to ensure that the person you care for is being safely discharged, and both you and they are happy with leaving hospital and what happens next, including having the right support in place.

About your caring role and a Carer's Assessment

- ☐ You should be asked by one of the clinical or discharge team *if you are willing and able to carry on caring for this person.* There may be parts of the caring role you are willing to continue, and parts you are not.

If you are not able to carry on caring, they need to listen to you and adjust the discharge plan while considering both your and the person you care for's concerns and wishes. This is in line with the Care Act 2014 (see p25).

- ☐ Have you been offered a referral to get a Carer's Assessment? If you require this, and have not been offered, please speak to your ACS Hospital Carer Support Advisor, as they can refer you.

With a Carer's Assessment, you talk about the care you provide and the impact it has on your life, and you are informed about the support you're entitled to and other services that can help.

About the discharge itself

- ☐ An assessment on the ward should be carried out to see if the person you care for is medically fit to be discharged from hospital, and to understand what support they might need on discharge. This may require a home visit from an occupational therapist.
- ☐ Do you know who to talk to at the hospital about discharge? Have they spoken with you about it? Have you attended any discharge meetings?
- ☐ Have you got the contact details of the discharge/social care team?

What should happen during and post discharge?

- ☐ Do you have a copy of the discharge paperwork? This could be a detailed letter, or a more comprehensive care plan.
- ☐ Do you know which referrals have been made for post discharge treatment or support and who the contact person is for each?

About the patient's health and medications

- ☐ Have you been told about any medication changes? You should be advised of any and why they've happened including any discontinued medications, and any new medications and their side-effects.
- ☐ Have they been assessed by an occupational therapist or physio?
- ☐ Could they recover further if offered formal support or rehab?

About support at home, including care and equipment

- ☐ Has any required extra help at home been arranged? For example, a visit from the district nurse or paid care workers.
- ☐ Do you have the right contact information for the care company, if a package of care is in place, or the district nursing team?
- ☐ Has an occupational therapist spoken to you to talk about any equipment or adaptations needed?
- ☐ Has any new equipment been delivered/fitted, if not, when? For example, a raised toilet seat or hospital bed. And home adaptations can sometimes be made, e.g. **grab** rails in the bathroom and/or on any stairs.
- ☐ Have you received training for using any equipment? Find out from the hospital who can help, or ask us.

About funding for care

- ☐ For more information about eligibility for funding to assist with care costs, please see page 20-21.

Care plan notes

MEDICATION

REFERRALS

EQUIPMENT

EMERGENCY PLANNING

CONTACT INFORMATION FOR OUR PACKAGE OF CARE

Post discharge reminders

Follow up appointment contact information

Name	Number	Email	Notes

Completed referrals:

From the hospital

-
-
-
-
-
-
-

Things to discuss with the GP

Any recommended referrals, change in medication, or other matters to follow up with the GP

-
-
-
-
-
-
-

Your cared for may be eligible for support with funding longer-term care

If the person you care for is assessed as needing support from the local authority, a financial assessment will be carried out to determine whether the person will be required to contribute towards the care costs of any support provided by the local authority. When being offered care/support, check if there is a funding implication.

The Surrey County Council website provides information on financial assessments linked to paying for care provided by Adult Social Care <https://www.surreycc.gov.uk/adults/paying-for-care>

Community Care – via the local authority

Most people who are discharged from hospital will not be eligible for CHC or Funded Nursing Care. However, they may be eligible for a Needs Assessment from the local authority.

The support provided could range from equipment, adaptations to the home, to a paid care worker providing personal care support. The hospital discharge teams work closely with adult social care and can request the needs assessment to be completed as part of the discharge assessment.

Reablement Care

This is a short period of support normally four weeks but can be up to six weeks, which is focused on supporting the patient to help regain their independence at home.

As the period of support nears an end there should be a reassessment to determine whether someone has ongoing care and support needs.

Other options

There are some other funding options available depending on meeting

Funding for longer-term care

the strict medical criteria. These include for adults aged 18 and over:

NHS Continuing Healthcare (CHC)

NHS continuing healthcare is a package of care for people who have a 'primary health need' that is provided by the NHS. The package of care can be provided at home, in a nursing home or a personal budget.

The eligible criteria to receive CHC is extremely high and most people with ongoing care needs will not qualify for CHC. However, if it seems like the person you care for may be eligible for CHC funding then an initial checklist assessment should be completed, this will often be completed post discharge.

For more information on NHS Continuing Healthcare please visit <https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare/>

NHS Funded Nursing Care (FNC)

If the person you care for is not eligible for NHS CHC, but they are assessed as requiring Nursing Care from a registered nursing care provider, they may be eligible for NHS Funded Nursing Care.

This means that the NHS may pay a contribution towards the cost of their registered nursing care.

For more information on NHS Funded Nursing Care please visit <https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-funded-nursing-care/>

Palliative care

Should your cared for be referred to the palliative care teams, please also see our booklet *Supporting Someone at End of Life* for additional information and support.

You can also enquire about referrals into your local hospice. Hospices provide a variety of support, which can include help to keep your cared for at home if this is their wishes.

After a hospital stay: key reminders for carers

You should also look to do the following:

- ☐ I have registered with my GP as a carer

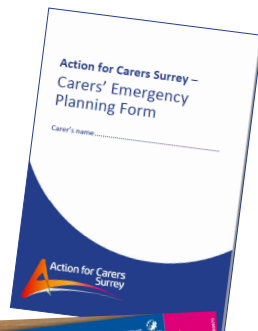
This is really important, as the GP needs to understand your situation and any additional pressure you're under. You'll also have access to additional help, such as flu vouchers. Just ask at reception.

Emergency Care

- ☐ I have completed an *Emergency Care Plan*

Contact Action for Carers to email or post a copy of this comprehensive form, or you can get it on our website. It lists everything your cared for needs, and the support you give them, in case you are unable to care.

- ☐ I've shared my plan with others – e.g. my GP, family, Social Care, care agency, etc.
- ☐ I'm registered with Crossroads Care Surrey for its Emergency Service. This will give you a special card to let others know you are a carer in case of emergencies. If you haven't ask your ACS Hospital Carer Advisor, or call our Helpline, about getting a referral.
- ☐ I've ordered my Carers Card from Crossroads Care Surrey. This lets others know you're a registered carer and provides some discounts. To order, email enquiries@crossroadscaresurrey.org.uk or call 01372 869970.



Carers' Assessment review

- ☐ I've arranged a Carer's Assessment review

If you previously had an Assessment, but things have changed following the person you care for's hospital stay, have you arranged a review of your Carer's Assessment? Please get in touch if you need help with this.

It shouldn't happen, and is rare, but things can go wrong

Medication

If after leaving hospital you notice any issues with the person you care for's medication, contact your GP surgery for help. If you are expecting medication from the hospital that has not arrived, contact the ward they were discharged from.

Package of Care

If you have been told that you have a package of care in place and they do not turn up as expected, contact the care providers directly if you have their details, otherwise contact the hospital discharge team or adult social care.

Complaints

If you are unhappy with the care or support received in hospital please contact the Patient Advice and Liaison Service (PALS) for the hospital.

You can find contact details for your local PALS on this government site <https://www.nhs.uk/service-search/other-health-services/patient-advice-and-liaison-services-pals>

Share your views and experiences

Luminus (the home of Healthwatch Surrey and the Giving Carers a Voice programme) are always seeking carers' views and experiences of health and social care in Surrey. They are keen to hear about your experiences, good and bad.

Find out more on their website: <https://www.healthwatchsurrey.co.uk/giving-carers-a-voice/>

Cared for's future wishes – ReSPECT form

Your cared for's future wishes

The person you care for may be very unwell and may have certain views on their future care.

ReSPECT form

A form called ReSPECT is used to state these views.

It allows patients to be part of the decision-making process and document their wishes, fears and who they want to speak for them if they are unable to do so themselves.

DNACPR (Do Not Attempt CPR) is part of this form, but the form contains much more than this. It is not a legally binding document.

For more information, please visit: www.resus.org.uk/respect

Changing over time

Please note that the ReSPECT form is a 'fluid' document. It can be updated and changed at any time, but is there as guide.

If you notice the information on the form is incorrect:

Please contact your GP or community matron/district nurse (if you have one involved) immediately for them to discuss and action adaptations

The image shows a ReSPECT form template. The form is titled 'ReSPECT Recommended Summary Plan for Emergency Care and Treatment'. It includes sections for patient information (Full name, Date of birth, Address, NHS/CHI health and care number), a section for '1. This plan belongs to:' (Preferred name, Date completed), a section for '2. Shared understanding of my health and current condition' (Summary of relevant information, Details of other relevant care planning documents), a section for '3. What matters to me in decisions about my treatment and care in an emergency' (Living as long as possible matters most to me, Quality of life and comfort matters most to me, What I most value, What I most fear / wish to avoid), a section for '4. Clinical recommendations for emergency care and treatment' (Prioritise extending life, Balance extending life with comfort and valued outcomes, Prioritise comfort, clinician signature), and a section for 'CPR attempts recommended' (CPR attempts recommended, For modified CPR, Child only, as detailed above, CPR attempts NOT recommended, Adult or child, clinician signature). The form also includes a footer with the website 'www.respectprocess.org.uk' and a version number 'Version 3.0 © Resuscitation Council UK'.

What you need to know about the Care Act and why it is important



Care Act
2014

The Care Act 2014 – the basics

The Care Act 2014 (which went live in 2015) brings in important change to the responsibilities local authorities have in providing care and support to both adults with needs (the person you care for) and you as the unpaid carer that supports them. For the first time in law, carers have equal rights to support as the person they care for.

Knowing about the Care Act is important to you for two reasons:

1. It helps you get the right support in place for the person you care for.
2. It helps you, as a carer, get the right information, advice and support.

It's all about wellbeing – and that means yours too!

The Act also signifies a shift from thinking about meeting people's care and support needs by offering and fitting them into pre-existing services, to looking at their specific needs and offering more personalised support to meet them.

What does the Care Act mean for you as a carer?

It gives significant rights for carers in England including:

- A focus on promoting carer wellbeing.
- A duty on local councils to prevent, reduce and delay need for support, including the needs of carers.
- A right to a Carer's Assessment based on the appearance of need.
- A right for carers' **eligible needs** to be met.
- A duty on local councils to provide information and advice to carers in relation to their caring role and their own needs.

Legislation and guidance

- A duty on NHS bodies (NHS England, clinical commissioning groups, NHS trusts and NHS foundation trusts) to co-operate with local authorities in delivering carer support.
- Consultation with you, the carer as part of the discharge from hospital process.

Other helpful legislation and guidance

The government's guidance on hospital discharge:

<https://www.gov.uk/government/publications/hospital-discharge-service-policy-and-operating-model>

NHS guidance on hospital discharge:

<https://www.nhs.uk/nhs-services/hospitals/going-into-hospital/being-discharged-from-hospital/>

Guidance from other charities:

Age UK's website (ageuk.org.uk) search 'hospital discharge'

https://www.ageuk.org.uk/globalassets/age-uk/documents/factsheets/fs37_hospital_discharge_fcs.pdf

Carers UK's website (carers.uk.org) search 'Coming out of hospital'

<https://www.carersuk.org/help-and-advice/practical-support/coming-out-of-hospital>

An independent organisation called **Beacon** helps people navigate the Continuing Healthcare process. You can call them for free advice on 0345 548 0300, or read more on their website <https://beaconchc.co.uk/>



Need help or support? Please get in touch.

Call us on 0303 040 1234

(or text on 07723 486730)

or email CarerSupport@ActionforCarers.org.uk

Action for Carers Surrey

We provide information, advice and support for carers of *all* ages, right across Surrey.

Our support includes benefits advice, advocacy, guidance on moving and handling, workshops, events, support groups, drop-in Hubs across Surrey, resources and more — giving carers a little time out and helping them feel less stressed, and more in control.

We have specialist support for young carers and also provide training and support for professionals working with carers.

Find out more at www.actionforcarers.org.uk

THANK YOU to the carers who have contributed to this booklet. If there is something we should add, or if you've any comments at all, please let us know.
Email CarerSupport@actionforcarers.org.uk.

Action for Carers Surrey

**Call us on 0303 040 1234; email
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Text on 07723 486730**



www.actionforcarers.org.uk

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