

for family and friend carers



Hospital Handbook for Unpaid Carers

# Hospital Handbook for Unpaid Carers

Top tips and tools for family and friend carers

A hospital stay can be daunting for a carer and the person you care for. An unfamiliar hospital setting, lots of medical-based conversations, the different procedures and not knowing what will happen with your loved one's care can be upsetting and stressful.

We have put together a few simple tips for your hospital stay alongside some tools to help you organise the information you receive and help you prepare for your conversations.



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# **About Carers Support West Sussex**

Carers Support West Sussex is a local charity assisting more than **30,000 unpaid carers** in the county. We recognise that being a carer comes with many different challenges.

We have a range of carer support services that can help you, from emotional and practical support to benefit advice, wellbeing funds, carer groups and a Carer Helpline.

#### **Our Hospital Service**

We cover all acute and community hospitals serving the county and identify and support carers where they are caring for someone who is a patient, or they may be a patient themselves.



# Our carer support services in hospital

During a hospital admission, whether it's planned or an emergency, we understand it can be a challenging time for everyone involved. Carers Support has a dedicated team who work in partnership with hospital staff to support you and the people you look after.

### Navigate Hospital Systems

Help you connect with teams and services to access appropriate support for you and the person you look after, ensuring you feel included in your hospital journey.

#### **Communicate Your Needs**

Help you articulate your needs and wishes concerning discharge and communicate with hospital staff on your behalf when appropriate.

#### Manage Wellbeing

Address practical matters and support you to manage your own wellbeing, including discussing the benefits of a Carers Assessment.

### **Fast Track Support**

Quick access to benefit advice and information about potential funding opportunities.

### **Emergency Planning**

Plan for future emergencies and access the Carer's Emergency Contact Card scheme.

### **Ongoing Support**

Connect you to wider support including the Support at Home after Hospital Service providing up to 6 weeks' practical support following discharge.



# 8 Essential Tips for Carers in Hospital

Over the next few pages, we will take you through the detail of these tips. We have summarised them here so you can reference the tools most relevant to where you are at in your hospital stay.

Prepare for Your Hospital Stay

Planned or unplanned, use our checklist to help you think about what items will be useful during your hospital stay and who you might need to notify.

Write Down Key Information

Note conversations, contacts and planned steps so that you can refer back, organise and digest information. 2 Introduce Yourself as a Carer

Share relevant information about the person you care for. You have rights as a carer - ensure you are known to hospital staff.

**Ask Questions and Clarify** 

Don't hesitate to ask about treatments, medications, and next steps.



### Look After Your Wellbeing

Look after your own wellbeing. Caring for someone in hospital can be demanding physically, mentally, and emotionally.



### Be Involved in Planning

When someone you care for is getting ready to leave hospital, it is important to make sure you are involved to ensure the process is safe and well planned.



### **Know Who to Contact**

After discharge, ensure you know who to contact for follow-up care if circumstances have changed or aftercare is needed at home.



### Plan for Future Emergencies

Be prepared by completing an emergency plan and having a hospital bag packed for any future stays.

# 1. Prepare for Your Hospital Stay

#### **Essential Items' Checklist**

Being prepared with practical items can help your comfort during a hospital stay. If your hospital trip was unplanned, see if friends or family can assist in gathering items.

- Glasses, hearing aids, and walking aids as needed
- Any regular medications
- Nightwear and comfortable day clothing
- Dressing gown and slippers
- Towels and toiletries
- Mobile phone and charger
- O Books, magazines, notebook and pen
- Personal identification and medical correspondence



■ Valuables: It is recommended not to bring valuables to the hospital. Ask a relative to take them home.

Medicine: If you bring medication, inform the nurse upon arrival so appropriate storage arrangements can be made. Notify the nurse of any known allergies to medicines.

### Practical Considerations When Admitted to Hospital

# Notify Important Contacts

Inform family, work, and friends about the hospital stay. Arrange for care of dependants, pets, or home responsibilities.

#### **Benefits and Support**

Contact relevant helplines if you receive benefits such as Attendance Allowance, Carer's Allowance, or Disability Living Allowance, as payments may be affected by extended stays.

### **Emergency Contacts**

Keep a list of important contacts including family, GP, social worker, and ask about support available to carers at the hospital or ward.

## 2. Introduce Yourself as a Carer

Staff won't always fully understand your role as a carer or the contribution you make, so it is important to communicate your role clearly from the beginning.

01

#### Introduce Your Role

Clearly state that you are a carer and explain your relationship to the patient and your involvement in their care.

02

### Share Key Information

Provide details about the person's normal condition, what has changed, medications, and your observations of the situation.

03

### Request Involvement

Ask for regular updates, request to be involved in care and discharge planning, and record names and roles of staff you speak to.

## Your Rights as a Carer



# Recognition & Involvement

Hospitals should identify carers early and involve them in discussions about care and discharge planning. Ask how you will be involved.



#### **Carer Passports**

Some hospitals offer Carer Passports with benefits like out-of-hours visiting and food vouchers.



#### **Communication Rights**

You can request to be included in care conversations and have the right to advocacy support.

# 3. Write down key information

In hospital settings, patient care typically involves a multidisciplinary team of professionals. It is helpful to document discussions, conversations, and planned actions so that you can refer back to your notes and ask follow-up questions.

### Record Sheet: Capture your conversations using this format

Date	Staff Name & Role	Summary of Discussion	Actions/Follow -up

Tip: Keep your notebook handy during ward rounds and key discussions. Don't be afraid to ask staff to repeat information or spell names - they understand the importance of clear communication.

## Record Sheet: Capture Your Conversations

Date	Staff Name & Role	Summary of Discussion	Actions/Follow -up

# 4. Ask Questions and Clarify

A patient and their carer can receive a lot of information which might seem confusing or unclear. Don't hesitate to ask clarifying questions - it's important that you understand. Here's some examples.

#### **Admission and Initial Care**

- Can you explain what the current diagnosis is and what it means?
- What tests have been done so far, and are there any still pending?
- Who is the main doctor or consultant responsible for their care?

#### Communication

- Who should I speak to if I have concerns or questions about their treatment?
- Can I be present during ward rounds or key discussions?
- How can I make sure my views as a carer are taken into account?

#### **Treatment and Medication**

- What medications are they currently on, and have any been changed since admission?
- Are there any side effects we should watch out for?
- Is pain being managed effectively, and how can I help monitor it?

### More questions to consider...

#### **Daily Care and Support**

- What support is available for personal care, and can I help with any of it?
- Are there any routines or preferences I should share with staff?
- How is their nutrition and hydration being managed?

#### **Discharge Planning**

- When will discharge planning begin, and how will I be involved?
- What support will be in place once they leave hospital?
- Will there be a follow-up appointment or community care referral?

# Mental Health and Wellbeing

- How is their emotional wellbeing being supported?
- Are there any signs of confusion or distress that staff have noticed?
- Can I speak to someone about dementia-friendly or trauma-informed care?

## Managing Challenging Conversations

Conversations with hospital staff can be challenging for unpaid carers. It can be hard to speak up, especially when staff are busy or using medical terms that are hard to understand. Your voice matters—your insights and concerns are important.

Consider these approaches to get the best out of a challenging conversation:



#### **Prepare Before the Conversation**

- Gather relevant documents (care plans, medication lists).
- Write down key points and desired outcomes.
- Organise support for the conversation (family, advocate, or support worker).



#### **Stay Calm and Assertive**

- Use "I" statements (e.g., "I feel concerned...").
- Maintain a respectful tone.
- Take breaks if emotions run high.



#### **Be Clear and Specific**

- State concerns plainly: Be specific about issues and needs. Use plain language and avoid vagueness.
- Repeat key points if necessary.
- Ask for clarification in simpler terms.

#### Use Questions to Guide the Conversation

- "Can you help me understand why this decision was made?"
- "What are the options available for discharge planning?"
- "Who can I speak to about a second opinion or escalation?"

### Worried about Deterioration?

As a carer, your observations are invaluable. If you notice a decline in the person you're caring for, follow these practical steps to ensure their needs are met and concerns are addressed effectively.



#### Speak to the Care Team

Share your concerns clearly and calmly with the primary care team. Use specific, factual observations such as, "She hasn't eaten in 24 hours." "He appears more distressed and in pain", "She is breathing more rapidly than normal." Your direct observations are critical.



#### **Activate Martha's Rule**

Request a rapid review by a different clinical team if you remain worried the patient's health is getting worse and your concerns are not being addressed. Hospitals provide clear instructions on how to do this—look for posters or ask a staff member for the dedicated contact number to activate

Martha's Rule.



#### **Assessment & Action**

Once Martha's Rule is activated, a separate medical team will assess the patient. This can lead to critical interventions, such as adjustments in care plans, transfer to a higher level of care like intensive care, or other urgent actions to stabilise the patient's condition.

# 5. Look After Your Wellbeing

Caring for someone in hospital can be challenging—physically, mentally, and emotionally. You need energy and strength to care for someone else. Where possible, try and look after your own wellbeing.

#### **Take Care of Your Body**

- Eat regular, healthy meals
- Stay hydrated throughout the day
- Rest when you can even short breaks help
- Move your body go for a short walk

#### **Look After Your Mind**

- Talk about your feelings with friends, family, or support groups
- Ask for help when you need it
- Notice signs of stress and respond with deep breathing, mindfulness, walking or music

#### **Know Your Limits**

- Say no if you're asked to do more than you can manage
- Let staff know if you're struggling or need a break
- Seek support from carer services and professionals

Remember: Looking after yourself is not selfish; it's essential.

# 6. Be Involved in Discharge Planning

When someone you care for is getting ready to leave hospital, it is important to make sure you are involved to ensure the process is safe and well planned.

Ask yourself these questions to check you are ready!	Yes or no
Have I / the person I care for, taken copies (or photos) of the care and support plan?	
Has or will the hospital send the discharge letter to the GP?	
Have I got a medical certificate (fit note)?	
Have we been given any medication as well as instructions and information? How many days supply do we have?	
Do we have the contact names and numbers for services arranged? (Either in the community or interim care provisions via the NHS or Health and Social Care.)	

Do we have details of any follow-up medical appointments and referrals?

Is transport in place?

If the cared for has been given a new diagnosis was I given information on this?

Is there any information we need to know about a special diet?

Have I been told about any change in support that the person I care for will now require? Do I understand this? Do I think I will cope with this?

Has the equipment required been delivered or when should I expect this?

If I have an issue in the first few days of discharge who should I contact?

(i) If care or support is not in place as planned, or you feel the person is unsafe, contact the discharge team. For safeguarding concerns, contact your local council's adult social care team.

## Checklist: Getting the Home Ready

Have clothes ready

Check on transport arrangements to get home

Have your house keys to hand

Ask for valuables to be returned

Have any necessary adaptations been made / equipment readied

Check if the heating has been turned on at home

Stock up on food and essentials

Arrange for extra help at home if required.

Prepare a comfortable space for recovery.

# 7. Know Who to Contact After Discharge

After discharge, it's crucial to know who to contact for follow-up care if circumstances have changed or aftercare is needed at home. Having the right contacts ensures a smooth transition and continued support. Ask as part of discharge for contact information so you know what you are doing.

#### **Hospital Discharge Team**

For questions about the discharge plan or if something isn't working as expected in the first days after discharge.

#### **GP and Community Teams**

For medical concerns, medication questions, or issues with arranged home care services.

# Carers Support West Sussex

For ongoing carer support, including our Support at Home after Hospital Service providing up to 6 weeks' practical support.

# 8. Plan for Future Emergencies

Being prepared for future emergencies can significantly reduce stress and improve outcomes for both you and the person you care for.

#### **Emergency Contacts**

Keep an up-to-date list of important contacts including family, GP, social worker, and hospital support services.

#### **Carers Contingency Plan**

Contact Carers Support to complete a plan that outlines what happens if you become unwell or unable to provide care.

#### **Hospital Bag**

Prepare a hospital bag with essentials in advance and keep it easily accessible.

#### **Medical Information**

Keep up-to-date medication lists and medical information readily available.

Tip: Review and update your emergency plans regularly to ensure they remain effective

## Record Sheet: Capture Your Conversations' template

Date	Staff Name & Role	Summary of Discussion	Actions/Follow-up

## Contact Us -



Ask a member of staff to refer you to us, or choose your favourite contact method:



Helpline

0300 028 8888



Website

www.carerssupport.org.uk



**Email** 

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