

Discharge from hospital

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(These suggestions should apply to any discharge from hospital. However, please be mindful that facilities and procedures vary greatly by location.)

Discharge plan, assessments, and involving the patient and their family/carer

Planning for discharge should start from the moment you are admitted to hospital. The aim of discharge planning is to identify and put in place the support you need after discharge.

Patients can be discharged:

- at home without any health and social care provision
- at home with provision of care and support from family or a home care agency
- to an intermediate facility such as a rehabilitation unit
- to a nursing facility for those requiring 24-hour support

Ideally, before discharge, patients should be assessed. This will usually involve a multidisciplinary team such as occupational therapists, neurologists, neuropsychologists, physiotherapists, speech and language therapists, dieticians, social workers, etc. Following those assessments, the needs and services required should be included in the discharge plan. On some occasions (e.g. transfer to a rehabilitation unit), these assessments are continued after discharge from hospital, but it is important that these assessments are initiated before discharge. Referrals for after discharge should be in place to meet the patient's needs before discharge happens and services specified in the discharge plan should be informed.

The patient and/or their carer need to be involved in the discharge planning process and decide what is realistic so that any discharge plan is as achievable as possible. Assessment of living conditions should also take place if the patient has any needs that may require housing adaptations or new equipment.

Encephalitis – a hidden disability

Some people affected by encephalitis are left with some degree of acquired brain injury (ABI). The nature of these difficulties (e.g. cognitive, emotional rather than physical) means that patients may not spend a long time in hospital. Consequently, some of these difficulties may appear later after the patient is discharged. Other difficulties may not appear to be significant and it may simply be assumed that the return to former life will not be problematic. However, issues can intensify becoming more apparent when people are trying to return to work, education and home life. It is therefore important to secure some method of follow-up after discharge and/or have the contact details of someone (e.g. neurologist) who the patient or patient's parent/guardian can turn to if these problems appear.

Becoming a carer

If the patient is discharged home, a relative may decide or find themselves to be in charge of their care. They don't need to do that, but if they do, they need to think carefully of all the implications. Being a carer is a big responsibility.

Your relative may have physical, cognitive (e.g. memory problems), behavioural and emotional difficulties. These issues can be complex and demanding for those providing care. As a carer you may need to provide personal care (e.g. bathing, eating), healthcare (e.g. appointments, medication), emotional support, help with house chores (e.g. cleaning, cooking, shopping). You may need to balance the caring role with your job or other family responsibilities. It might impact on your employment and possibly affect income. You may also have your own needs to think about (physical and/or emotional). In conclusion, you need to make sure you know what the process of caring for your relative means and what you would need to do before you are starting this role.

Making informed decisions

If the discharge involves transfer to another facility or home care, the patient and their family/carers will need to make some decisions regarding which service/ location will be best. Costs and finances will also need to be considered. The discharge process is often subject to time constraints, and this can put carers under pressure to make decisions, so make sure you get all the support and information before you make these decisions.

If insurance is involved, you will need to check directly with the hospital or your insurer to find out what might be covered and what you will have to pay for.

Make sure you get copies of these plans and keep careful records of your conversations. It is always worth stating at the meeting that you require to have a copy of those notes made available to you. Any concerns regarding the discharge can be raised with the person in charge of the care and/or a patient organisation within the hospital if there is one (e.g. PALS in England or PASS in Scotland).

When a patient has encephalitis and another medical condition managed by different healthcare providers, open communication between those providers is vital for holistic and coordinated treatment of both illnesses. Since ABIs or cognitive impairments may hinder patients from effectively coordinating their own care across multiple providers, a patient advocate such as a family member may need to take on the critical role of ensuring clear dialogue and collaboration transpires between all members of the healthcare team.

Checklist for discharge

Ideally at discharge a few things need to be in place:

- Full information about the illness and after-effects and what to expect in the next few days but also long-term given to the patient and their families/carers. This also includes the effects of the illness on returning to driving, work, school, physical activities and travelling. It is important to note that families of a patient may also have to take time off work or their social lives to care for the patient. If the patient is a child, you will need to know about any future vaccinations.
- Carers should know exactly what is expected from them.
- Details about what problems may arise, what is considered normal and what to be worried about, what to do or who and how to contact a health professional to get support.
- Future follow-ups and referrals.
- Detailed information about medication prescribed including the side-effects.
- Services and support that have been agreed and that will be in place for you returning home: providing care at home, community nursing visits, day care services, any possible equipment or adaptation needed to your home.
- Details of any voluntary organisation that may be able to provide further information and support (e.g. Encephalitis International).

People who need on-going support will be discharged to assess. The focus will be transfer to community rehabilitation rather than in-patient rehabilitation settings.

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Thank you!

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