

PREPARING FOR A HOSPITAL STAY FACTSHEET

This factsheet is based on conversations with beneficiaries who have been in hospital and advice from our Medical Advisers to help make your hospital stay and convalescence as hassle-free as possible.

No one likes the idea of going into hospital, but it really helps if you're prepared for both your stay and for the recovery period.

Not all hospital staff understand the full impact that losing the use of a limb or stomach muscles may have on you, even if it is only temporary, but taking a few simple steps can help them understand and meet your needs.

Q I am going in for a planned treatment or operation. How can I prepare?

A With a planned treatment, you are likely to be called in for a pre-planning meeting or pre-operative assessment. Make the most of these by discussing with the doctor or nurse any needs you might have whilst in hospital (both immediately after the operation and once you have recovered fully from the anaesthetic – as they may be different) and/or when you leave hospital.

It can help to take a list of what you might find difficult and what might make it easier for them to look after you; and to follow up with a written summary of what you have agreed, afterwards. You may also want to request specific tools or aids, for example, you may request a bed with remote control or make sure you have access to a specific dressing stick.

Send the summary to the secretary of the consultant in charge of your care and ask them to forward it to the appropriate staff, to make sure you get what you need.

The Trust has also written some information for anaesthetists and surgeons on treating a thalidomide affected individual, so you may find it helpful to take this information with you as well as sending to the surgeon in advance of the operation. This information can be found here: www.thalidomidetrust.org/for-professionals/emergency-care-surgery-and-anaesthetics/

Q What kind of things should I tell the hospital team?

A Examples of what you might include in the conversation or summary are:

- Difficulties doctors and nurses have had in the past taking your blood or blood pressure or inserting things into your veins, such as cannulas (thin plastic tubes to give drugs and fluids). You could let them know the best place to take blood/blood pressure from you or best place to put a cannula (if you know). You could also take the factsheets on taking blood and blood pressure produced by the Trust with you. You can find this here: www.thalidomidetrust.org/health-and-wellbeing/health/health-appointments/taking-blood/
www.thalidomidetrust.org/health-and-wellbeing/health/health-appointments/blood-pressure/
- Any bad reactions you have had to medicines and/or anaesthetics.
- Any problems you have had in the past with being intubated (where they put a breathing

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tube into your throat) or with procedures like epidurals.

- Neck, back, shoulder or joint problems that may affect how you are handled or positioned on the operating table. If you don't usually find lying or sleeping on your back comfortable, think about how your body may react to being in this position for several hours. Things like propping your knees up with pillows may help. Speak to the anaesthetist or surgeon if certain positions are uncomfortable for you or you know cause you pain. You may want to discuss this with one of the Medical Advisers prior to admission. They could write a supporting letter about positioning in surgery.
- Adaptations that may be needed to hospital equipment, such as walking frames and crutches. The Trust can give you information on this.
- Any help you will need with eating, drinking, dressing, or going to the toilet (e.g. cutting food up, giving you a drinking straw, beakers with handles and/or lids and spouts). It is worth noting that reaching your water can be difficult as operations often greatly hamper bed mobility. The Trust can help make a laminated sign to go above your bed with important information. Straws in hospitals are disposable so you may want to take in your favourite type.
- If you have a short reach, ask the staff to clip the emergency button to your pillow, so it's always in easy reach and doesn't fall down.
- Potential mobility issues that you might have after an operation.

Q What should I take with me?

A Things to take into hospital with you include:

A few days' supply of your current medicines and a list of your medicines and dosage. It's easy for busy hospital staff to lose track of your medication needs so it's good to take them with you, with a list of what you take, and how much. You'll need to hand in all your medicines when you're admitted to hospital except, perhaps, for minor things like Savlon or skin cream. It's also worth taking a picture of your current prescription on your smart phone or tablet to refer to if paperwork gets lost.

Any essential gadgets or aids you use at home to help with things like eating, drinking, dressing, toileting, bathing, communication, or sensory issues. Label them with your name and address in case they get lost. Before you go into hospital, ask the ward staff if you should take your own, bigger items of equipment, or use theirs.

Handy items like wet-wipes, alcohol gel, hand-wash, tissues, pens, puzzle books, playing cards, and cash. Some people find that earplugs help them sleep, and a dressing stick or grabber may be useful to reach things from the other side of a bedside table.

Drinks and snacks, like small boxes of fruit juice with straws, bottled water, snacks and quick energy-boost foods, so that you don't have to rely on staff to provide them between meals.

Your mobile phone. There is a myth that mobile phones can't be used anywhere in hospital. This is only true on some cardiology (heart) wards, some of the time. However, it's worth checking with ward staff first. Do remember to bring your phone charger too.

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Entertainment. While big laptops might not be practical, tablets such as iPads are usually fine (but bear in mind the later point about things going missing in hospital).

Toilet paper. Hospitals often use single sheet dispensers, so you might want to take your own!

It's also useful to take along any information medical staff might need from you, including:

A written summary of your medical history, investigations, results, and treatments. The Trust can provide some of this information and you can also ask your GP for a printout of the summary from the practice record. It's best to take multiple copies so that one can be put in your medical notes and you have a spare in case the first one gets lost. You might want to consider using the website, 'MyLiferaft' to store this information electronically and create a 'hospital passport'. This is the same company that helped develop the Trust's emergency card: www.myliferaft.com

Any NHS letters you've received about your visit. The hospital should have copies in your medical notes, but they sometimes go astray.

Do not assume that information you've given to one staff member will be passed on to others. You might have to repeat yourself!

Q Are there any other things I should bear in mind?

A Here are a few more tips: -

- Things often go missing in hospital, especially things like spectacles, teeth, and hearing aids, so label everything and keep an eye on it. Do not wrap valuables in tissues as staff often throw them away for hygiene reasons.
- Flowers are seen as infection risks and are not allowed on many wards.
- Find out the direct phone number of your ward so that if you cannot get a nurse's attention you can call them up from your mobile... probably not popular, but effective!
- Take a printed copy of this advice sheet with you.

Q What if I'm not happy with how I'm being looked after?

A If you are unhappy about your care while you are in hospital, discuss it with ward staff.

If that does not help, write your complaint down and hand it to the ward staff - keeping a copy yourself. Remember to include the fact that you have already talked to people about the issue in your written statement. The Trust have written some information regarding making a complaint here: www.thalidomidetrust.org/my-account/resources

Every hospital now has a PALS (Patient Advice and Liaison Service) system in place, with staff who are there to represent your interests. They are the best people to contact if you are not getting satisfaction at ward level. Sometimes just asking ward staff for the contact details of PALS makes them consider your complaints more carefully. PALS also appreciate good feedback so do let them know if you had a positive stay or if a particular member of staff was helpful.

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Q What about when I leave hospital?

- A** You might need equipment you have never needed before while you recover from your operation. You may be able to borrow equipment from your hospital occupational therapist or physiotherapist, or have adaptations made whilst you are still in hospital. You may want to discuss with the physiotherapists the particular movements you make e.g. twisting or bending of the neck or back to check you are ok to make them post operatively. They may want you to avoid certain movements, depending on the operation you have had, so it's important to check with them before you leave.

Take a look at the equipment information on our website under 'Everyday Living'. It includes information on eating and drinking, going to the loo, washing, dressing and mobility: www.thalidomidetrust.org/health-and-wellbeing/making-life-easier/equipment/

Or call the Health and Wellbeing team, who can send you information.

If you need it, there is also the option to rent equipment such as hospital beds, mattress elevators and other items from a private supplier such as:

www.medequip-uk.com

www.arjohuntleigh-medicaldirectory.co.uk

Q What if I need additional help when I'm discharged?

- A** A bit of forward planning can make life easier when you get home. You may need to ask a family member in advance if they can look after you if you think you will need extra help on discharge.

Hospitals should not send you home until you can manage your own care, like washing or dressing, or until you have care arranged at home, either by the hospital or a family member or PA.

Intermediate care is provided free of charge for people who no longer need to be in hospital but need extra support to help them recover. It lasts for a maximum of six weeks and can be in your own home, a community hospital or nursing home. The hospital should be able to arrange this for you but tell them early on if you'll need it. If you are having any problems, please contact the Trust.

Q Will I get any paperwork when I leave hospital?

- A** You'll be given a letter for your GP, which is called a discharge summary. This will provide information about what happened during your hospital stay, changes to medication and what follow up care you may need. This may be sent directly to your GP. If not, give this letter to your GP as soon as possible.

If you're given any medication to take home, you'll usually be given enough for the following 7 days or 14 days.

If you need to keep taking your medication, make sure you arrange to get a repeat prescription from your GP before your hospital supply runs out.

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Some surgeries require up to 2 working days (48 hours) notice for repeat prescriptions.

Q **Where can I get further information?**

A If you have any further questions or concerns, you can call the Health and Wellbeing team on **01480 474074** or email hello@thalidomidetrust.org