



Arabella's guide to long hospital stays

By MPS Society member Emily Rogers,
based on her own experience.



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What to take

Each hospital is slightly different. If you have specific questions, don't be afraid to ask the specialist nurse at your hospital.

Preparing for a long stay in hospital for a bone marrow transplant or gene therapy can feel overwhelming, especially when you are unsure what to bring or who to ask. Based on our experience and input from other families, we have compiled a list of items you may want to consider.

Emily

Staying comfortable

✓ Bedding for parents

Hospitals never have enough pillows. Duvets can be a luxury that some parents like to take with them but the hospital will provide a parent bed for one parent. A nurse will often make the bed up for you but you also have access to a linen cupboard and you can ask the hospital staff for spare blankets.

✓ Comfy shoes for parents

Many parents opt for Crocs or similar shoes for wearing around the hospital. Depending on your own circumstances, you may want to take shoes suitable for going on walks outside the hospital. If there are two parents staying in the hospital, you can take it in turns to go for walks.

✓ Bibs

Mucositis, an inflammation of the mucous membranes that line the mouth, can make little ones very dribbly, so a stack of bibs is useful.

Toys

There is plenty of variety as hospital play teams will provide toys and have lots that you can switch. We found it useful to have a few favourite toys of our own. Once you are admitted to the BMTU (Bone Marrow Transplant Unit), your little one can spend hours connected to infusions, so toys suitable for a cot, like stickers, mess-free colouring or coloured sticky tape for creating patterns, are great.

Check your home insurance. Ours only allowed 30 days unoccupied but approved longer as we informed them in advance and arranged for someone to check the house.

✓ Comfy clothes for all

You are going to be spending a lot of time in the hospital. So parents and little ones need comfortable clothes. Some families have found that two-piece pyjamas work best for their children to easily access the central line (a tube in a large vein near the heart). Others opt for vests to keep children from touching it.

You will have lots of time too. Take something that does not require mental effort, e.g. books, crosswords, drawings or embroidery.



Making the hospital feel like home

✓ Blu-tak

Being able to attach paper on the walls of your hospital room can be convenient. If you are in a hospital where you can stay in a charity house (e.g. Ronald McDonald House Charities) you will be able to receive mail, so friends and family can send pictures or cards. Putting a big sheet of paper on the wall to collect questions for the doctors helped us keep track of what we wanted to ask.



✓ Hanging shelves

Most hospital rooms have a wardrobe and a few cupboards. You might find that shelves for folded clothes are more useful than hanging space.

✓ Tablet / laptop

Most hospital rooms will have a TV but not all of them. If you have a tablet or laptop, it can be worth taking one with you.

Take a tray to carry food and drinks from the parents' kitchen to your room.

✓ Toddler snacks

The hospital will provide meals for your little one and nurses will usually be able to offer light bites any time. However, we all know toddlers can be fussy eaters. If there are particular, individually wrapped snacks that they love, it could be a good idea to take some.

✓ Parents' snacks

The wards will have parent kitchens where you can heat up meals, usually there is a microwave, kettle, fridge and toaster. You will be able to go out to buy food in supermarkets and your hospital team will advise whether you need to avoid busy times, wear face masks, ensure regular handwashing, sanitising or other protective measures. Hospitals also usually have food outlets on site.

✓ Lunchboxes

If there are two parents and you are able to stay in a charity house, you will have access to a full kitchen with your own fridge space. Some parents have found it helpful to cook a meal and carry it over to the hospital room. So lunchboxes to transport the food are practical.

You could also take:

- **Pushchair** for walks
- **Laundry bag** as the hospital will only wash the patient's clothes but there will be facilities for your clothes.
- **Sun hat and cream** as the chemo makes your little one more vulnerable to the sun.
- **Steriliser** for bottles and baby cups

Top tips from other parents



Don't be afraid to accept help that is offered to you. If you can take a break and have some time to yourself, go for a walk, even if you are just sitting in the parents' kitchen, having time out of the room can really help.

Be prepared to be flexible. Depending on the hospital, you may find that you are going to need to move rooms from time to time. Although it can be unsettling, it could be a positive because your little one is making progress in their treatment.



Don't forget that you don't have to take everything with you. Amazon is your friend and everyone's hospital experience is different. What works for one family isn't necessarily what you need.

“It's much easier said than done but try to take things one step at a time.



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