

Advice for surgery from patients and carers

- After my son's surgery (ependymoma 4th vent) he lost all sense of balance and was very disorientated e.g. He did not know whether he was upside down or not. We found that massaging his arms and shoulders with baby oil or lotion helped him to keep him 'grounded' for want of a better word. It kind of 'connected' him to the rest of the world and soothed him greatly.
- If the doctors tell you that surgery will be 3 hours - add on a couple more in your head. They told us 2-3 hours and it was actually 5. I understand that this is quite common. That extra 2 was a very worrying time, especially when no-one tells you what is happening!
- I wish somebody had warned us that symptoms may get worse before they get better, and not to give up hope. I know of somebody who woke up completely paralysed which was absolutely terrifying, but within 2 days she was walking again and within a few weeks you would never have known that there had been a problem - she went on to study for a degree and bring up her two children. Some of the damage may be permanent but not all of it, the difficult thing emotionally is not being sure which will improve - try and take the attitude that all symptoms may disappear!
- Ask for therapies to help recovery. For example speech therapy, physiotherapy and others are available through your hospital but sometimes you have to ask to get them. Be honest with your medical team and let them know how the patient really is – don't make out things are better than they are or they won't be able to assess how much help you need.
- Don't be afraid of being a 'nuisance'. If you want to know something - ask. There is no such thing as a silly question.
- If you see something you are not happy about - check it. For example, my son had a wet patch on the back of the neck of his pyjamas - it transpired his sutures were leaking spinal fluid, which had not been noticed by the nurses.
- Try to organise visitors on a rota basis so that the patient doesn't get too tired, and also to ensure that the carers can take a planned break.
- Eating was an issue immediately after the surgery - we found that my son did not want to chew at all, so things like creme caramels, that slipped down easily with no effort, were good.
- Try to be around at mealtimes to help the patient eat - and ask to see a dietician about some shakes, or even the ward sister for a drip, if they are having trouble eating after their surgery. It is all too easy for food to be placed near a patient who can't feed themselves, then for it to simply be taken away again later without staff having noticed that it hasn't been touched.
- My son's vision was impaired badly immediately after surgery, so watching TV or reading was out of the question. We found story tapes helped pass the time for him, as did his ipod or mp3 player with his favourite music on.
- If nausea is a problem ice lollies seem to be better than drinks - it helps keep the fluid intake up without the effort of drinking, and if you make them from freshly squeezed fruit juices then you are also getting some vitamins.

- Hospitals do not generally advertise it, but if you are visiting every day for a matter of weeks they do often offer a special rate for parking. For example, St.Georges at Tooting charged £2.00 a hour for parking but offered a rate of £10 a week if you got the ward sister to sign a special form that they give out. Ask at the ward desk for more information.
- Even a biopsy can cause swelling in the brain and increase the risk of seizures. It is sensible to ensure that the patient has somebody with them at all times for about a fortnight after any surgical procedure. Therefore don't worry if you have never had seizures before but get one/some at this point – they may well disappear again as the brain heals itself.
- After surgery, my son did not want to see any visitors for a long time and seemed depressed. We discussed it with his counsellor and she agreed that it would be a good thing to ring his best mates (just one or two) and arrange for them to come anyway. Our son never knew that we arranged that visit (he would kill me!), but it broke the cycle. After that he was OK. But you would need to think carefully before you do it. That may not work for everyone.

Contributors:

Linda Rickford

Katie Sheen

Emma Chamberlain

Do you have some advice that we could add to this page? If so, please email us – contributions can be anonymous if you would prefer them to be.