

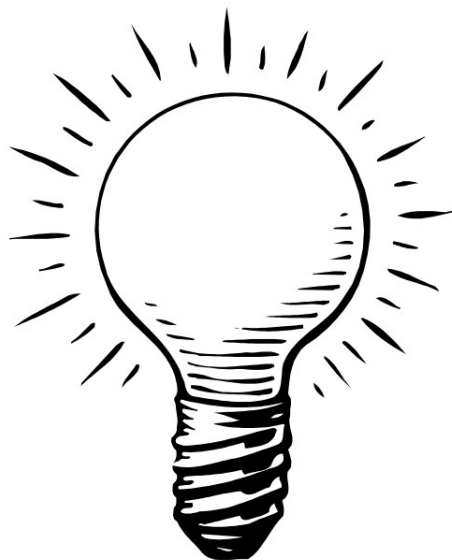
Having a Bone Marrow or Stem Cell Transplant—Top Tips

Bone Marrow Transplant Unit
Information for patients

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Top tips

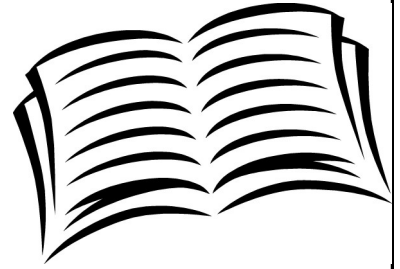
The “top tips” in this leaflet were suggested by a patient. If you or your friends and family have any of your own tips, please let us know so that we can include them in future editions of the leaflet.

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1) Do your homework

- Before you come into hospital for your transplant, read all the literature that your doctors and nurses have given you. Some of the information may not seem relevant straight away, but it will help to prepare you for what is to come. Encourage those family and friends who will be supporting you and visiting you to read it too. If you experience any side effects, having read about them in the literature will remove some of the fear factor for them.



2) Be a patient patient!



- Do everything that the doctors and nurses ask you to do. They will know your limits - they have looked after many people having transplants and will be able to assess your progress, and know what you should be able to do.
- In hospital, planned daily schedules can go out of the window, as health care staff attend to the needs of other patients. This is particularly the case on a highly intensive unit, such as the Bone Marrow Transplant Unit (BMTU).
- Do not use the panic button too soon or too much. When your infusion stops, and the alarms sound, try to wait until a nurse comes - they will!

3) Getting through the day

- Give yourself little goals, and reward yourself when you achieve them. Don't overdo it - you will get very tired and it is frustrating not being able to achieve something because you set too high a target for yourself.
- Keep a small notebook or journal and write down your progress or events that happen - particularly things that make you smile. Look for the silver lining in any situations-reading it over later will not only bring back that smile if you are feeling a bit down, but you will also get a sense of the progress you are making. This is particularly important when you come to doing your physio.



- Although your room becomes your domain and you will personalise it, try to de-clutter as much as possible. It can be frustrating when you can't find something and "I know it was there five minutes ago".

4) Coping with change

- Try, within the bounds of your strength, to retain some control over personal hygiene. Even if you feel really tired, it is nice to be able to take the cloth from the nurse and wash your own face. Having said that, in hospital, the first things that disappear are dignity, pride and embarrassment. The staff will make it easy for you to handle this.
- Remember that if it all gets bit much-particularly in the middle of the night-the nursing staff will spend time listening to you, your fears and concerns.
- Remember that you are not alone on this journey. Throughout the UK, and indeed the world, others share your path 24/7.
- Try to get a good friend or partner to handle stuff outside hospital, such as banking and home maintenance. Getting bogged down in such things can induce a sense of frustration, particularly if you can't get something resolved.



- Before the transplant, the chemo will mess up your sense of taste and/or smell. Hospital food, which tends to be well balanced but bland, will probably taste horrible. It does improve as you get your taste back.

5) Fighting boredom

- Make a list or schedule of visitors you are expecting - try to organise it so that you can look forward to visitors without wearing yourself out. Time can hang heavily and visitors mostly bring joy.
- In the early days of treatment, whilst you are coming to terms with where you are, try to make your room your domain, accept the reality of where you are. Missing home comforts, home cooking, your partner, can be really upsetting if you allow it to be.
- Try to give yourself a small project while you are in hospital, something to give you a focus and use up some of those waiting hours.



6) Moving on

- Don't expect to suddenly get better - everything takes time. Do the daily physio, trying to go one step further each day, but don't get frustrated if you have a day off. There seems to be an unwritten rule of "two steps forward, one step back", and on that third day you may find yourself lying in bed unable to do very much.
- Heal at your own rate!
- You will feel some trepidation when the staff finally give you a discharge date. You've had all these weeks of being looked after, now it feels like you are on your own. You are not. Follow up reunites you with your team, and is very regular.

Never be afraid to ask.

Good luck!



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