

X-Linked Lymphoproliferative Syndrome

Preparing a child for a Bone Marrow Transplant

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Introduction

The following is a list of key tips for preparing your child for a bone marrow transplant regardless of the underlying condition which is being treated. Some of the tips should also be helpful for adults preparing for transplant. This leaflet is based on our own personal experience of taking four sons through five bone marrow transplants for XLP—our family story can be found at www.teamhartley.co.uk

If you have any queries on the content of this paper then **please check with your own medical staff.**

IMPORTANT—BMT treatments will differ from hospital to hospital and country to country and the protocol will change over time, so please take what we say here as a generalisation only.

1. Fatten up your child

Often children going into transplant have limited 'fat' on their bodies due to the underlying condition. However it can be expected that a child will loose upwards of 10% of their body weight during the transplant process. There will be times when they will not want to eat, or possibly with a sore mouth or throat (caused by the chemotherapy) simply unable to eat. And the weight does seem to drop off very quickly.

So do all you can to add the kilos before transplant, if you can 'fatten up' your child it will potentially make the transplant and recovery period easier.

For example, we deliberately commenced an overnight 'milk feed' (in our case using a brand called Modullin) prior to their transplant to add on weight. This also proved useful for helping to prepare their stomachs for the affects of the chemotherapy ahead— many XLP boys have quite ulcerated stomachs as part of the condition and we found that the 'milk feed' was very good for this as well as adding weight.

2. Get them drinking

Prior to the first transplant we thought that our boys did 'drink well' but were surprised at the additional volumes they were expected to consume once in hospital. Because of the need, particularly through the chemotherapy stage, to 'flush through' toxins and to ensure that the liver remains working well. It is very useful to ensure that your child is a good drinker.

For example it is expected than an 8 year old would drink around 1.7 litres of fluid a day (water, milk, squash, juice etc.) and a 12 year old

facing the journey you have ahead.

13. Returning Home

For a family going through a BMT the 'end of the road' is the joyous day when the new marrow is working sufficiently well to allow the child to return home.

This is itself a huge day and can be quite daunting after being 'cushioned' by having an experienced team of medical experts looking after your child each day.

But it is a huge and significant day so rejoice!

However it is not the end of the road. It can take up to 2 years for the new marrow to 'catch up and learn' and fully replace what was there before. It is highly likely that your child will require one of more lengthy stays in hospital post transplantation with either an infection or some form of Graft vs. Host Disease (GVHD). Three of our four sons all had lengthy stays post their transplant.

14. Be Strong

Going through a BMT with your child is far from easy and will be a highly stressful time. It is important that you take it one day at a time and 'be strong' for your child each day. Children are very good at detecting changes in their parents and carers—so hang on in there!

There will be times when you will need to walk away and cry (including us men) but it is our firm opinion that you must remain strong and positive for your child.

Personally for us, our Christian faith gave us a firm foundation to take this long painful journey on. We do not claim to even guess why we have gone through such a tough time but hope that our experiences will help others on their own journey.

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key times (such as transplant day and if your child becomes seriously unwell) when you will both want to stay close by.

It is worth talking with your hospital about the possibility of them providing some form of accommodation for you close to the hospital.

10. Over Christmas and the New Year

We would recommend that if the transplant is scheduled to go over the festive period that you check exactly what consultant, dietician, immunology etc. cover will be available. We had a distinct impression that significant parts of the hospital 'shut down' for 10 days and access to key personnel was not easy over this time. Talk this through with your medical team.

Our experience of spending two Christmas' on the transplant ward was overall very positive and the children are well entertained and showered with presents.

11. Ask lots of questions

There will almost certainly be 'swings and roundabouts' as you go through transplant..... And there will be times when you have great concerns over how well your child is doing. Ask the medical team to be brutally honest with you and to share detail. We have always found them to be most obliging and they do find the time to sit down and listen to your concerns and answer you fully.

And always ask for clear clarification of any points you don't understand particularly when the consultants and doctors are in 'bone marrow speak'. Going through a bone marrow transplantation will expose you to a huge new vocabulary which can be very daunting at first.

12. Expect the unexpected

After going through five bone marrow transplants with our sons a key learning has been to 'expect the unexpected'.

Despite the boys having the same chemotherapy regime they each reacted to their BMT's in different ways—and no two transplants were alike.

Things can and will change rapidly and a child can go 'downhill' very quickly and equally recover just as quickly.

It is impossible to fully prepare for all of the rigors of a BMT. We have found that taking it 'one day at a time' to be the real only way of

Around 2 litres. The actual amount is dependant on their body weight at time of transplant and will be advised to you by your medical team.

Also please be aware that they will not be able to drink tap or bottled water during their transplant and for a significant time afterwards. Our experiences have been that the sterile water which is provided on the ward tastes nothing like normal tap or bottled water. So we would recommend that you ensure that you child can drink water with a squash (orange, apple, blackcurrant etc.) This hides the taste and flavour of the sterile water and makes the water much more palatable.

3. Summer clothing

We strongly recommend that you check with the ward your child will be on what will the temperature be like during their stay. Despite the time of year you will almost certainly find that the ward temperature will be mildly tropical. So ensure that both you and your child dress appropriately. We have found that whilst on their particular ward the boys wore shorts and t-shirts for most of their stay.

If you are looking at a transplant date in the autumn or winter be prepared to buy 'summer clothes' when you can. We had the acute problem of trawling Oxford Street in London trying to find shorts in December!.

4. Lots of pyjamas

For children not in nappies you should prepare to bring in a large supply of pyjamas and particularly pyjama bottoms. The children are likely to suffer from acute diarrhoea at some point during their transplant and 'accidents' will happen particularly at night or when they are sleeping during the day. We have had 'bad nights' when we have gone through 4 and 5 pairs of pyjama bottoms.

For young children who are recently out of nappies it would be worth trying to persuade them to go back into nappies for the duration of their transplant.

We would also recommend that you buy these well in advance of the transplant date, particularly if you are due to go in during the autumn or winter where finding short pyjamas will not be too easy.

5. Short hair

One day around 7 to 10 days after the transplant day, your child's 'party piece' will be pulling out clumps of their hair...and you wake up one morning to find the child wearing what looks like mohair pyjamas. We found the most effective way of removing the hair was to use a pair of

electric trimmers once the hair loss started.

For most boys the inset of loosing hair is no big deal, but we suspect that this is not true for most girls.

Do try and ensure that their hair is as short as possible when they first come in for their transplant, as there will be less to loose.

6. Consider a PEG

A PEG or Percutaneous Endoscopic Gastrostomy is something that most parents facing taking a child through bone marrow transplant should seriously consider for their child. This is a small medical procedure that in effect puts a semi permanent tube (the PEG's can be used for up to 5 years if necessary) straight into the child's stomach. All 'oral' medicines and feeds can go through the PEG rather than having to be swallowed.

It is particularly useful if your child has had bad experiences of NG (Nasal Gastric) tubes or struggles to swallow the medicines they are currently on. Also it is likely that at some point after the chemotherapy your child will have a very sore mouth and throat and so having a PEG really then comes into its own.

The PEGs have also proven to be very useful post transplant when they still require large numbers of medicines and overnight feeds.

For our eldest son it was the thought of an NG tube that really 'freaked' him out, and with the 'smoothness' of how the PEG has worked for all our sons we would have no hesitation in recommending them for other children.

The downsides are that your child will need a small operation and over night stay to have the tube fitted and in time removed. Because the stomach may be 'pumped up' to allow the initial insertion operation this can be uncomfortable. Plus it does mean an additional operation, and this also has risks.

But we do strongly suggest that you seriously consider it for your child and talk to your medical team.

7. Become an entertainer

You can expect your stay in hospital for a BMT to take between 6 weeks and up to 3 months (the later being the time our eldest son stayed in) This is a long time for active children and whilst there may be times when they don't want to do anything, there will also be very long Sunday afternoons and more.

So try and plan ahead and think through activities that you can do together. For many parents and carers you will never have so much quality and personal time with your child as this—use it. For our boys we invested in various craft type activities (model planes for the eldest, drawing and crafts for the second and third and magic tricks for the youngest). We even developed a '1001 things to do with a sick bowl'. Check out if there is a games machine (PS2, Xbox, Wii) in their room and computer access.

You should also stock up on a good supply of DVD's as there will be times when your child doesn't want to do any activities at all. Encourage friends and school mates to write in and possibly even send small gifts. The arrival of the post is one of the highlights of the day on the ward.

Find out what support you will get on the ward—for example whether a play specialist will be available or a school teacher. The ward our boys stayed on also had a wonderful music lady and regular visits from clown doctors.

8. Look after yourself

Whilst all of your attention will rightly be on your child, it is important (actually essential) that you and any others carers for your child stay in the very best possible health. If you are unwell you will not be allowed on the ward because you will be an infection risk for your child and others.

Ensure that when you are on the ward that you drink and eat well and that you try and leave the hospital each day for a good walk. Ensure that your child understands the need for this. Most supermarkets now do an excellent range of healthy microwave ready meals when you become tired of the hospital canteen (about day 3).

If your child's transplant is over winter then you should consider having a flu jab to keep you well.

9. Work out a rota

Every parents or carers situation is different, but for us living about 100 miles from the hospital and having three other boys at home, sharing the time in hospital works well. We found that between 4 and 5 days on, and the same number off was about right for us. Some parents and carers alternated daily and some had the relative luxury of having both carers there full time.

Discuss what will be best for you with your partner but be prepared to be flexible particularly if one of you becomes unwell. There will also be