

General advice

Alcohol gel versus hand washing

There is little evidence to suggest which method of cleaning your hands is more effective at killing germs than the others. However, soap and water is more effective than alcohol gel at reducing the viruses that cause stomach bugs.

We recommend soap and water if your hands are dirty, you have touched animals, or after going to the toilet. If your hands are visibly clean, alcohol gel is probably sufficient.

Building work

While your child is receiving treatment you should not have any building work at home that will expose your child to brick dust. Brick dust contains tiny airborne spores that can cause infections. If exposed to these your child will also be more susceptible to developing a lung infection. Please speak to your child's consultant if you are considering having any building work done at home.

Cleaning and personal hygiene

It is important that a general, good standard of cleanliness is maintained in the home. Keep floors and surfaces clean, especially in the bathroom and kitchen. Regular vacuuming and wiping down surfaces with hot soapy water is sufficient. Bedding and towels should be changed weekly.

Each of us has a level of bacteria on our skin and in our digestive system that does not cause any harm. However, after chemotherapy people with a reduced immune system can get infections from these bacteria. Good hand washing and personal hygiene are the best ways to combat infection.

Compliance with medicine taking

Throughout your child's treatment they will need to regularly take oral medicines, both while in hospital and at home. This can be difficult for the child and for you, as the parent giving the medicines. Please speak to either your POONS or a nurse on the ward if your child is experiencing difficulties taking their medicines, as ordering medicines in alternative form (such as tablets or syrup) may help. The play staff can also support and advise you on how to manage this.

Contact sport

It is important to try to keep active. However, as a result either of treatment, tumour site or surgery, certain activities such as contact sports may not be advisable during intensive treatment. There may be risk of a central line being pulled out or bruising if platelets are low. Talk to your child's consultant to find out what sports are appropriate. If your child plays a sport regularly, consider alternative ways they can remain involved, such as being a referee or score keeper.

More information can be found in 'General information for care of central lines' under 'Potential central line problems' in the **RED** section.

Emergency clamps

You will be given a clamp for use in case of emergency, such as the bung falling off or the line splitting. Your child **MUST** have this clamp with them at all times.

Fatigue

Some children experience excessive tiredness (fatigue) when they are receiving chemotherapy and radiotherapy. If your child experiences this please ask for an information leaflet and also discuss with either your doctor, nurse or POONS, who will be able to provide you with further advice.

Fish tanks

Stagnant water is a breeding ground for many different types of bacteria. If you have a fish tank you should follow manufacturer's instructions and clean the tank out regularly. Your child should not do this job.

Flowers and pot plants

If you have cut flowers at home you must replace the water daily. Stale water harbours bacteria that can cause infections. Soil is also a source of bacteria and mould, so digging or playing in soil should be avoided. Flowers and plants are not allowed on Piam Brown ward.

Gloves

Whilst your child is receiving intravenous chemotherapy, we advise that you wear non sterile gloves when changing and disposing of nappies. If administering oral chemotherapy at home, normal household rubber gloves kept for this purpose only can be used.

Going on holiday

Please discuss any holiday or travel plans with your child's consultant. We generally advise that children on treatment do not travel abroad. Special insurance is required if you do – we do not recommend travel abroad without insurance. For holidays or travel within the UK you will need a referral to the nearest hospital so we can provide both you and them with the required details in case your child becomes ill whilst away. These details should be obtained from Piam Brown day ward, your POONS or your local hospital.

GP

We will send your GP discharge summaries, but they will not be able to advise regarding your child's care. Continue to use your GP as usual for yourself and the rest of your family. You should contact your local hospital for your child whilst they are on treatment. Your local children's community nurse may ask your GP to supply prescriptions, dressings or syringes, which you may need to collect from your GP's surgery.

Hair loss/alopecia

Hair loss is a common side effect of many different chemotherapy drugs, and can affect children in different ways. Older children and teenagers can find it an embarrassing problem that can affect their body image and self-esteem, particularly when with friends and peers.

Normally it will take a few weeks before hair starts to fall out, but it can take longer to completely fall out. Tips to help ease the process include:

- Cut long hair shorter before it starts falling out – we can arrange for this to happen while your child is in hospital
- Hair can be very itchy and irritating on the face and neck when it falls out, some children choose to take control themselves and shave it all very short
- Have fun experimenting with hats, bandanas and scarves

If you would like a wig, we can make an appointment with the wig fitter, who can help you to choose what will most closely match your child's natural hair colour and style.

Neutropenic diet

Once your child has completed all their treatment and their blood count has recovered, i.e. neutrophils are 1.0 or above, they may eat and drink as normal and you will no longer need to give them cooled boiled water.

Pets

If your family has pets please ask a nurse for the leaflet which will give further information. Ideally, you should not introduce any new pets into the home while your child is having treatment.

Hand washing is essential for everyone after touching or feeding animals, whether at home, on a farm or at a zoo. This is especially important for those on treatment.

Avoid contact with pet soiled areas when in parks/sandpits/gardens.

Returning to school/nursery

Going to school/nursery is an important part of your child's life both socially and for education. Unless you are advised otherwise, your child can usually attend even if they are neutropenic. The aim is for your child to return as soon as possible and your POONS will be able to advise them. Where it is not appropriate for your child to go to school, it may be possible to arrange home tuition. Speak to your POONS if you wish to discuss this.

Safe storage of medicines at home

Most of the medicines you receive can be stored in the cupboard, however, some medicines need to be stored in a fridge, so please check the label carefully.

All medicines should be stored out of reach of children.

Sand play

If your child goes to nursery, sand play is acceptable, as is playing on the beach. However, sandpits in gardens or parks should be avoided, as domestic pets and/or wildlife could potentially be making them dirty.

Sun safety

Children receiving chemotherapy and radiotherapy treatment are more susceptible to sunburn and the effects of the sun.

- Use high factor sunscreen (at least factor 50) on all areas exposed to the sun
- Replace your bottle of sunscreen every year
- Apply sunscreen to your child 30 minutes before going outside, and reapply regularly – especially after being in the water
- Your child should always:
 - wear a hat to protect their head
 - wear clothing outdoors
 - avoid the midday sun
- Your child should not sun bathe directly
- Remember, sun protection will be required while your child is at school in the playground.

Swimming

It is generally advisable that children with a central line or a PICC line do not swim. No child receiving chemotherapy treatment should use jacuzzis, steam rooms or hot tubs.

Syringes for oral medicines, nasogastric tubes and gastrostomies

Some syringes say single patient use, others single use. In hospital syringes are single use only i.e. used once and thrown away. At home these syringes are single patient use and can be used for up to 14 days if re-washed (up to 6 times a day) unless you have used them for oral chemotherapy.

When using any syringes for chemotherapy they should be thrown away after each use by discarding them into your cytotoxic sharps box, which your community nurse will dispose of. If you are unsure how you should be using your syringes please check with your local community nurse. Your local community nurse will supply you with syringes, feeds, dressings etc. that your child will need when at home. Occasionally they may contact your GP to prescribe these for you.

Water play

Indoor water play at school or nursery is acceptable, however, paddling pools in gardens and parks should be avoided.

Please speak to your doctor, nurse or community nurse if you have any questions.