

End of Treatment

Frequently asked questions answered

Your POONS will offer you a home visit around the time your child is approaching the end of their treatment to discuss any questions or concerns you may have and make sure you can make contact us if you have worries or issues once treatment has finished. We understand that the end of treatment can be a particularly difficult time and talking through your questions with your POONS can help to alleviate worries. If you need help accessing different services after treatment, your POONS will be able to signpost you towards them.

Future healthcare

Are children who have had chemotherapy at greater risk of getting other types of cancer?

If your child has been given chemotherapy (and/or radiotherapy), they are likely to have an increased risk of developing cancer in later life. Depending on the diagnosis and treatment received, the level of risk is probably similar or slightly more than that arising from damage to the lungs from smoking, or excessive sun exposure to the skin. This has been recognised and accepted as one of the consequences of a cure. Your consultant will discuss the risk at the end of treatment.

Can my child reduce the risks in later life?

Leading a healthy lifestyle can help to reduce the risk of developing cancer for everyone. It is important to:

- eat healthily (at least 5 portions of fruit and vegetables per day and a good fibre intake)
- drink alcohol in moderation
- exercise regularly
- keep your weight as normal as possible
- avoid smoking (active and passive)
- avoid excessive sun exposure.

Your child should take advantage of available health and cancer screening programmes such as cervical smears, mammograms, etc. and follow advice on regularly examining their breasts (women) or testes (men).

What potential symptoms should my child be aware of?

Report any concerning symptoms promptly to your GP or hospital doctor, including:

- swollen glands
- unexplained lumps anywhere on the body
- persistent unexplained pain
- persistent unexplained headaches, backache or nausea/vomiting
- concerning moles (particularly but not exclusively in the radiotherapy field)
- excessively pale, abnormal unexplained bruising
- abnormal bleeding from any site in the body.

Will there be something in the child's notes that stays there throughout their life to alert a GP to the diagnosis and treatment they have had?

You or your child should tell the doctor about their history, including past diagnosis and treatment, as it may be relevant in future.

At the end of treatment, an end of treatment summary document will summarise all the relevant aspects of the treatment. This letter will remain in the electronic notes and will be also be shared with your own doctor in your shared care hospital, your GP and also with you. This document can always be referred to when needed.

How long does it take for immunity to recover?

It will take 6 months for your child's immune system to fully recover to normal, over which time you should gradually notice the improvement.

When can immunisations be done?

Once treatment is finished, your consultant will discuss the most appropriate time to re-immunise your child with you.

Because children may lose immunity during treatment, we recommend booster doses of the routine childhood immunisations, usually six months after treatment has finished.

Your consultant will send a specific list of the vaccines your child requires to your GP.

Once blood counts have recovered, what should we do if our child has a temperature or feels unwell?

A lot of children still have their central line in the initial period after treatment. If your child has a temperature and still has a line, it is important that you follow the same advice as while they were on treatment. Please contact your local ward/day care area to arrange for bloods to be taken and for your child to be reviewed.

If your child's blood count is normal and they do not have a central line, you can give paracetamol for a temperature. Many families would want to talk this through – please call us or your shared care hospital.

For how long does the support from our shared care facility continue?

If you are worried about your child and would like them to be reviewed by a doctor, you will continue to have open access to your local unit for 6 months after the end of treatment.

During this time, your child will be reviewed regularly in the outpatient clinic and you will have the opportunity to discuss ongoing support there.

For many children, follow-up will continue for five years following the end of treatment, but your child's individual plan will be explained at their last consultation in Southampton.

What will happen to my child's follow up when they are 18 years of age?

Your child's aftercare once they are 18 years old will be planned through a transition planning process and will take into consideration the cancer sub-type and the type of treatment received (chemotherapy and radiotherapy). The care may then be in a teenage and young adult follow-up service in this hospital (in the short term), or be transferred to an appropriate adult service. Alternatively, your child may be discharged to your primary care service (GP) in your region.

Diet and nutrition

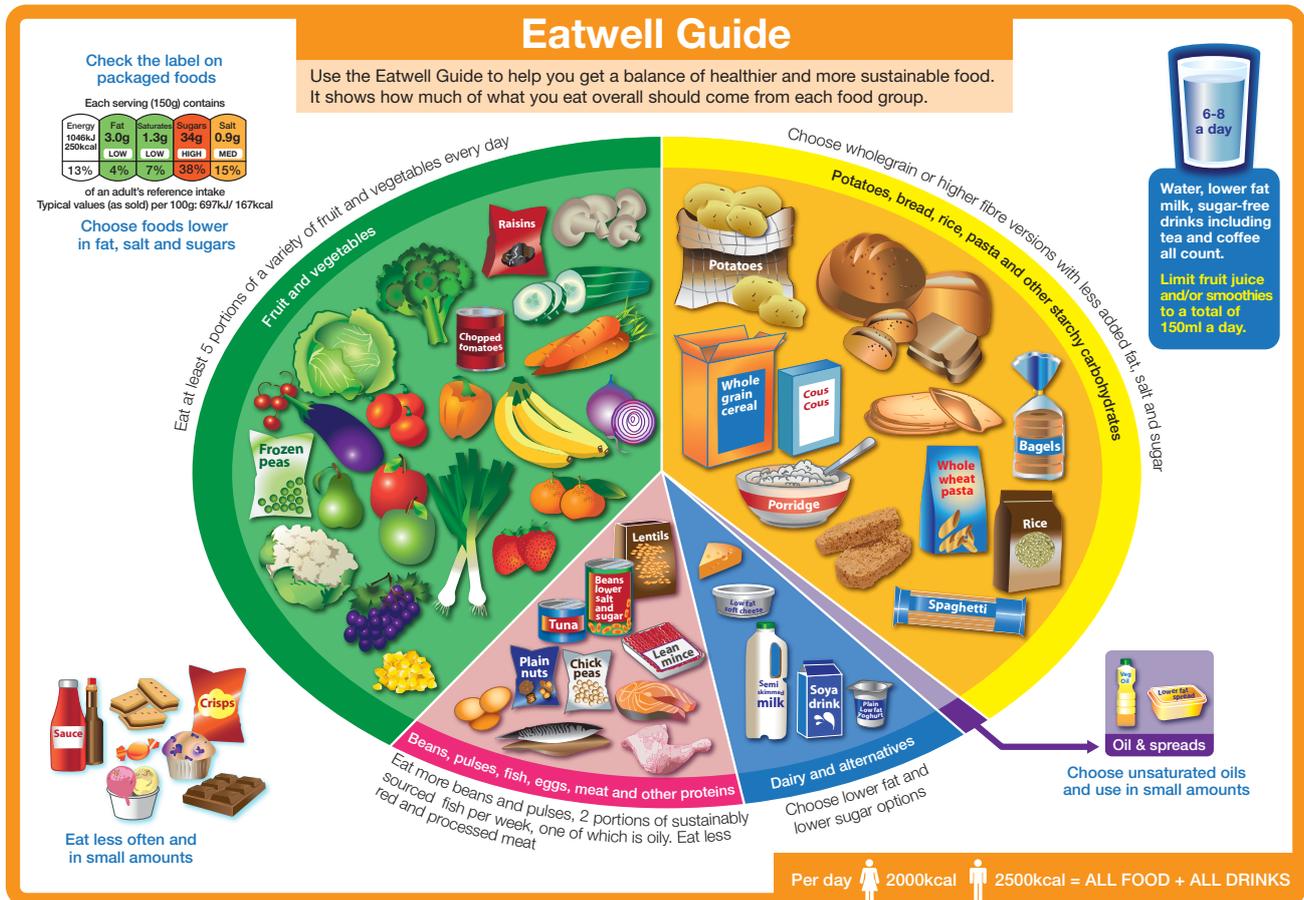
How long do we have to continue special diet/food preparation for?

We asked you to follow food safety guidelines throughout treatment to try to avoid any high risk foods for food borne infections.

Once your child has completed treatment and their neutrophil count has returned to normal (1.0 and above), these guidelines need no longer be followed. This also applies to water. Your POONS will be happy to discuss this further with you if required.

Is it safe to drink tap water when treatment has finished?

Once your child's blood count is normal, it is no longer necessary to follow the food safety guidelines, including those regarding water consumption.



What sort of diet should my child follow after treatment?

Your child's diet may have changed dramatically while proceeding through treatment, so a gradual return to a balanced diet is recommended. This won't happen straight away and changes to the diet can take a few weeks to months to achieve. Some children may still need to gain weight, while others may have gained too much. Try to base your child's diet around the Eatwell guide. If you are worried about your child's weight or diet, ask for an out-patient referral to your local dietitian.

Should my child take multivitamins?

If your child is eating a varied diet, a multivitamin tablet may not be needed. If you are concerned that any food groups are missing e.g. fruit and vegetables or dairy foods, a general multivitamin may be useful. It's usually best to use a brand with a range of vitamins and minerals, rather than just one; there are lots of different types available in chemists and supermarkets. Make sure you choose one that is appropriate for the age of your child.

Recommendations for Vitamin D deficiency prevention suggest all children and young people living in the UK are potentially at risk and should take an age appropriate Vitamin D supplement.

Mental wellbeing

When can my child go to school and what should the teacher be aware of?

Your child should be encouraged to gradually increase their school attendance as they slowly build their energy over the subsequent months after the end of treatment. If necessary, depending on the treatment, your POONS can also speak with your child's teacher if there are any specific issues.

How do we get our child back into a good sleep pattern?

When in hospital, children will often have had a parent or carer with them overnight so after treatment ends, sleep can be disturbed, particularly their settling alone again at night.

Rebuilding confidence to sleep alone is a gradual process. It can help to break this down into stages, offering stickers or tokens for younger children at each stage. Parents can also find it difficult to leave their child, particularly at night time, but encouraging this independence helps to reinforce that your child is now well.

Children who have just finished treatment are often not as strong physically as they were before. Gradually increasing their physical activity and school attendance can help towards rebuilding their fitness and stamina, and can also aid improvements in sleep and wellbeing.

How do we re-establish discipline?

When a child has been poorly, the normal rules about behaviour can become stretched. Although in some cases the illness may have happened fairly quickly, it is reasonable to expect that it might take a bit of time on recovery for things to return to usual.

Setting reasonable expectations for your child(ren) and yourself that will help you gradually work together towards your goals is likely to be more effective than expecting things to change overnight. Maintaining positive boundaries about acceptable and unacceptable behaviour and being consistent about these will help your child (and their siblings) to know that they are better now.

What about siblings who have had less attention or different care during treatment?

Brothers and sisters have also often had to adjust to significant changes over the course of treatment, while their parents' focus understandably needed to be on their poorly brother or sister.

Siblings are likely to continue to worry about their brother or sister after treatment finishes, and will need reassurance that things are better now. As they get older, they may need more information about what happened to their brother or sister and whether they could be affected too.

As the family adjusts, it may be helpful to make individual time for siblings to talk about their needs and worries, and to reassure them that their feelings are equally valued.

How long before we can stop worrying?

During treatment, the busy schedule of hospital appointments and the regular conversations with health professionals can help to distract parents (and young people) and alleviate worries. When the end of treatment arrives, alongside the relief, it is natural for parents to also worry about what happens next.

Expecting to have mixed emotions, and knowing that these worries are typical at this stage can be helpful in coping with them when they (inevitably) crop up.

Hopefully, as the length of time since end of treatment increases, the worries about your child's health in the future will gradually fade, but it would be unreasonable to expect them to disappear altogether.

Your child's diagnosis was probably one of the most traumatic things that your family has ever experienced. It will take time to adjust to the end of treatment, and to process and make sense of what you have all been through.

Life is unlikely to go back exactly to how it was before, but some families are able to reflect on their experience and notice positive impacts on their lives, such as feeling that they are more focused on the things that really matter to them in a way that they hadn't been before.

What should we do if our child finds needles tricky once lines are removed?

It is possible that blood tests may still be needed after a central line is removed. If your child will struggle with having a blood test, please talk to the play specialist in advance. They can help you and your child prepare with coping strategies and also to develop an individualised plan for your child to help the procedure go more smoothly.

How can we work on body image and self confidence with our child?

The illness itself, the treatment, and the changes caused by medications and side effects can often alter a child's physical appearance, sometimes significantly. Being unwell can also remove a child or young person from their normal activities and social relationships, which can erode their self confidence.

When children have finished treatment and are ready to return to school, sometimes they may become more aware of looking different to how they did before, or perhaps their strengths being different to how they were before they became ill. For teenagers particularly, they may strongly feel that they want to be seen as 'normal' and the same as their peers, but they may be very aware of feeling or looking different. Children may also have experienced changes in their friendship groups, or feel that other children have 'moved on' while your child was away from school.

Acknowledging these changes and encouraging your child to talk about them, either with you or with another trusted adult, can help them to adjust to the way that things have changed, and can help them to gradually look for signs of things feeling better, so that in time, their confidence and self-esteem can be rebuilt.

What is the best way to deal with the long term effects of steroids – weight gain, stretch marks etc?

Stretch marks are caused by rapid tearing of the skin. Over time stretch marks will fade but they will not disappear completely. Maintaining a healthy lifestyle with diet and exercise will help to reverse weight gain and improve the appearance of stretch marks.

It is important to maintain a healthy balanced diet with plenty of fibre, fruit and vegetables, cutting down sugary drinks and high calorie foods. Being physically active along with a good balanced diet based on the 'Eatwell Guide' (for children over 5 years of age) can also help your child manage their weight.

How do we know if we are not managing and need to get professional help? Where is this available?

It is difficult to be prescriptive about this, as we all react differently to situations and call upon different coping mechanisms to deal with the challenges life throws us.

If you feel that your worries about your child's health are significantly impacting on your ability to find your 'new normal', or you are concerned that fears and worries are driving isolation or restricting engagement in activities for you and/or your child, then please get in touch with your CLIC Sargent Social Worker and/or Clinical Psychologist.