latch

Yma ar gyfer canser plentyndod yng Nghymru | Here for childhood cancer in Wales

GIG CYMRU NHS WALES

Bwrdd Iechyd Prifysgol Caerdydd a'r Fro
Cardiff and Vale University Health Board

Going Home

Going Home

When a child is getting ready to go home from hospital, feelings of excitement may be mixed with feelings of worry for everyone in the family. Going home for the first time after diagnosis can be a stressful time, because everything is new.

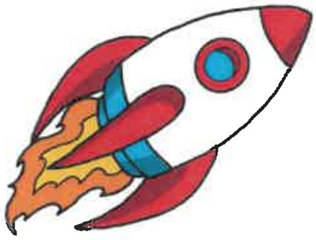
It is very important that before you go home you are given the information you need. This is particularly important in order to be able to recognise when your child is unwell and needs medical help. If you have any questions at any time, please ask.

Many demands are placed upon you during your child's cancer treatment. There will be hospital appointments, and you will provide care to your child at home including; giving medication, observing how much they eat and drink, limiting infection risk and watching your child for any side effects of their treatment.

This leaflet provides the information you will need to prepare you for a safe move from hospital to home.

Contact details

Rocket Outpatients



For general enquiries (Mon-Fri 9am-5pm) contact on **029 2184 8805**. Please ring this number for blood results. It is important to stick to appointment times when attending clinic appointments on Rocket.

If your child is unwell and you need nursing/medical advice and support, use the designated telephone triage phone line.

Telephone Triage Phone Line 02921 848804

Social Worker:

Paediatric Oncology Outreach Nurse Specialist (POONS):

Clinical Nurse Specialist (CNS)/ Key Worker:

Esther (Leukaemia – key worker) 07816138246

Vicki (Solid Tumour – key worker) 07812757762

messages can be left on these phones and will be prioritised and answered accordingly

Rainbow Ward

The inpatient unit is for children aged 0-14 years of age. Your child will receive chemotherapy treatment on Rainbow ward, however, if your child needs admission for any other reason they may be cared for on another ward within the Children's Hospital. This is not a decision taken lightly and we know this can be upsetting for families. You will still be cared for by the oncology/haematology medical team when on another ward.

Rainbow Day Beds

Your child will receive treatment in our day beds unit. There will be times when the unit is busy and treatment may need to be given on the basis of priority rather than the time you arrived. Please be patient.

Shared Care

We have Paediatric Oncology Shared Care Units (POSCUs) in Wales which allows children and young people with cancer to be treated closer to home. These centres are linked closely with your Principle Treatment Centre (Cardiff) and provide supportive care, help, support and some chemotherapy for patients. Your POONS will have links with your shared care hospital.

Our POSCUs in Wales are;

Location & Hospital	Ward	Telephone Number
Carmarthen Glangwili Hospital	Cilgerran	01267 229618
Swansea Morriston Hospital	Paediatric Assessment Unit	01792 285699
	Ward M	01792 618891

Central Line

Type of line (Circle): Hickman Line Port-a-cath PICC line

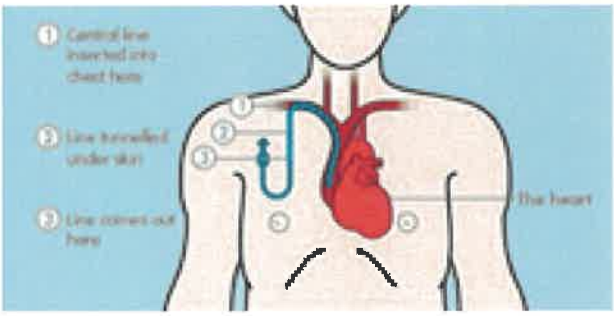
Size of port needle (if applicable):

Type of dressing:

For the first four weeks after having the central line put in, the exit site should be kept dry to allow for healing.

Always keep an eye on the site and if it is red, swollen or painful then contact Rainbow ward immediately for advice.

Hickman Lines



Dressing changes need to be done once per week, or sooner if soiled or damp. Flushing and hub change to be done once per week.

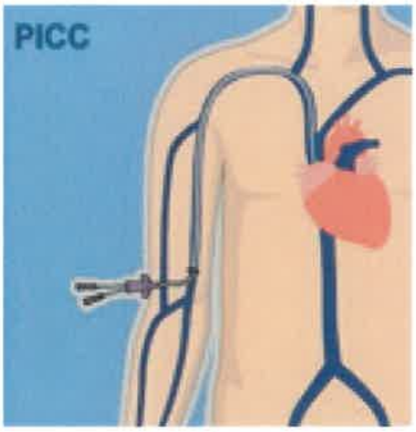
Flushing and routine dressing will be done by the POONS or when attending the Rainbow day unit or ward.

Parents can be taught to do routine dressing changes once the line is established – please speak to the POONS or Rainbow/Rocket nursing team for advice should you wish to discuss this.

Wiggly bags/wraps, we advise that lines are secured safely using these.

Showering/bathing, we advise your child should sit in a shallow, waist deep bath. Do not allow your child to submerge or soak in the bath.

PICC Lines



Dressing changes need to be done once per week, or sooner if soiled or damp.

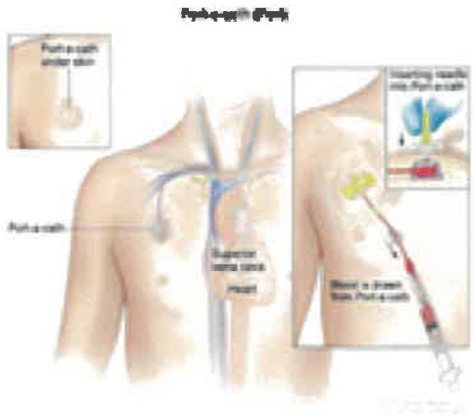
Flushing and hub change to be done once per week.

Flushing and routine dressing will be done by the POONS or when attending the Rainbow day unit or ward.

Statlock – will need to be changed every 2-4 weeks or sooner if soiled or damp.

Showering/bathing, we advise your child should sit in a shallow, waist deep bath. Do not allow your child to submerge or soak the line in the bath.

Port-a-Cath



This type of central line needs to be accessed with a port needle.

Once the needle is in it can remain for 1 week.

When not being used the needle can be removed.

The port will need flushed once per month if not used.

Showering/bathing – if the needle is not in place then your child can shower and bath as normal. However, if the needle is in, we advise your child to sit in a shallow, waist deep bath. Do not allow your child to submerge or soak the line in the bath.

Temperatures

A raised temperature is often the first sign of infection.

Although it is important to remember that a child with a low temperature (under 36 °C) may also have an infection.

The normal body temperature is 36–37 °C. At home you should check your child's temperature twice a day but also if you are concerned about them or feel they are unwell.

Please **phone the hospital immediately** via the designated triage phone number if your child has;

A temperature of 38°C or above on one occasion

A temperature below 36°C

Do not give your child paracetamol (Calpol) without medical advice as this can reduce a temperature and hide signs of an infection.

Ring the Telephone Triage Phone Line

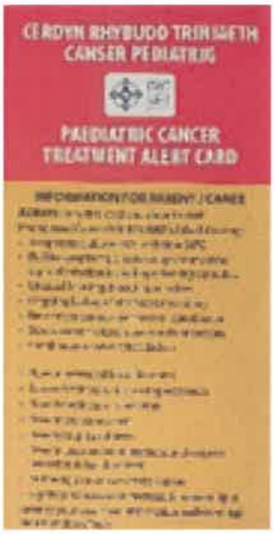
02921 848804

Thermometers - we advise a digital thermometer which can be used either under the arm or under the tongue. You should have one at home before being discharged from hospital.

Infection prevention

It is vital that your child maintains a normal life as much as possible. If your child is well with a normal temperature and the neutrophil count is 0.2 or above then they can attend school, nursery and continue most activities. This number may be different depending on your individual consultant's advice. However, it is normal to be concerned about your child catching infections when they are neutropenic.

This advice may change if your child needs a bone marrow transplant.



CERDYN RHYBUDD TRINIAETH CANSER PEDIATRIG

PAEDIATRIC CANCER TREATMENT ALERT CARD

Friends/family with infections (coughs, colds, diarrhoea and vomiting) should avoid visiting.

Please refer to **Paediatric Cancer Treatment Alert Card** for further information.

If your child comes into contact with chickenpox, measles, shingles or any other infectious disease then phone telephone triage line or your clinical nurse specialist immediately for advice.

To prevent infection **personal hygiene is important**. Bath or shower each day (using a clean flannel and towel), wash hands after using the toilet and before eating.

Mouth care - your child should brush their teeth twice a day with fluoride toothpaste using their own soft toothbrush. The toothbrush should be replaced at least every three months. If you or your child notice any mouth pain, sores, cold sores, bleeds, white spots or a coated tongue then contact the hospital for advice.

If your child uses a dummy/bottle you must make sure they are sterilised. Throw away any damaged teats.

All children will have a **dental assessment** after diagnosis. This is done at the dental hospital. Any treatment needed will be carefully planned with the Rainbow team.

Constipation, diarrhoea and passing urine - contact the hospital if your child has trouble going to the toilet.

Please observe the bottom area for redness or if your child reports pain. Avoid wet wipes as they can irritate the skin. We will give you advice on different barrier creams to use.

Contact the hospital if your child **feels sick or is being sick** or having trouble eating or drinking.

Please report all new skin changes or rashes to the nursing or medical team.

Listen to your instincts, if you feel your child is "not right" then contact the telephone triage line or your CNS for advice.

It is advised not to carry out any major building works on your home during your child's treatment, due to dust particles and risk of contracting an infection. We also advise that your child cannot play with soil. If they play with sticks and leaves outside then please ensure they wash their hands afterwards.

Hot tubs - please **DO NOT** use due to high risk of infection.

Cancer Treatment and Blood Cells

Bone marrow is found in the middle of many of our bones. It produces all the cells that make up our blood. Treatment for cancer and leukaemia will temporarily slow or stop the production of healthy cells in the bone marrow. During treatment, your child will usually need to have a full blood count (FBC) every week from a finger prick or a blood sample taken from the central line.

Cells affected by cancer treatment include:

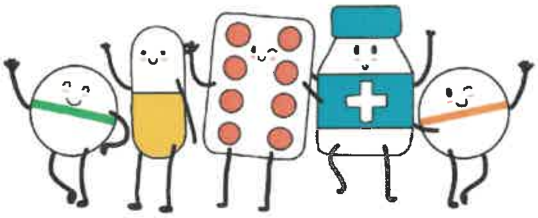
Red blood cells – these cells contain haemoglobin (Hb) and carry oxygen throughout the body. If the level falls below 70 then a blood transfusion may be needed. Symptoms to watch for include; tiredness, shortness of breath, lack of energy, feeling the cold more than usual, dizziness, headaches and looking pale.

White blood cells – the function of these cells is to fight infection. Neutrophils fight infections caused by bacteria. If your child's neutrophils fall below 0.5 then your child is said to be "neutropenic". Children who are neutropenic are more at risk of infections.

Platelets – are cells that control bleeding and bruising. When your child's platelet count is low they may bruise easily and have small pinhead red or purple spots on the skin. They may also suffer from nosebleeds or gum bleeding. If your child's platelet count falls too low then a platelet transfusion may be needed.

Medication

Never give Ibuprofen.



Only give paracetamol under medical advice. Contact the hospital if your child is struggling to take prescribed medications.

Anti-sickness medication

After receiving treatment please make sure you have anti-sickness medication at home or to take home before being discharged from hospital. Your child may need anti-sickness medication for 48 hours (or longer) after treatment.

When your child is admitted to hospital please make sure you bring with you any medication they are taking.
If you require any medications to take home always inform the nurses/doctors as early as possible. This includes during your appointment on Rocket. **We require at least 72 hours' notice to prepare prescriptions**

Sun Safety

It is important to take the right precautions to protect your child from the dangers of the sun. The medications your child is on may make your child's skin **more sensitive** to sunlight and ultra-violet (UV) rays.

Always wear sun block SPF 50. Apply 30 minutes before going outside and re-apply every 2 hours.

Avoid sunshine in the middle of the day when the sun's rays are at their strongest and please encourage your child to sit in the shade. Make sure your child wears protective clothing including a hat and sunglasses. Avoid de-hydration by encouraging your child to drink regularly.

Holidays

Discuss all planned trips with your Consultant. Provide your CNS/key worker with at least 2 weeks' notice in order to coordinate care with a local hospital and plan medications needed.

Pets/Animal Contact

It is fine to keep any pets you already have but they can be a source of infection. Your child should wash their hands after any contact with animals, this includes any farm or wild animals. Children should not have contact with animal faeces e.g. litter trays.

Do not allow your child to kiss your pet or let your pet lick your child. Keep the pet healthy with regular worming, flea treatment and keep vaccinations up to date.

It is recommended not to introduce a new pet into your home whilst on treatment.

See Children's Cancer and Leukaemia Group (CCLG) website "Pets" for further information.

Immunisations/Vaccinations

Children on treatment are not to have any immunisations apart from the flu and Covid 19 vaccination – you will receive a letter regarding advice on these.

Siblings may get vaccinations as normal but please discuss with your consultant prior to arranging these.

Your child will be re-vaccinated 6 months after completing their treatment.

Food Safety

Food should be well cooked eaten immediately.

Do not re-heat meat.

Bacteria in food will cause infection.

Takeaways – choose places with a good hygiene rating. Food should be freshly cooked. Avoid eating rice from a takeaway, it is better to cook your own fresh rice.

We will closely monitor your child's weight throughout treatment. Your child will be seen by a dietician on Rainbow ward and some children may need feeding support

(either supplements or a tube down their nose – NG tube)

There will be some limitation to what your children can eat when on treatment.

Please see food safety advice leaflet for patients with neutropenia for full details. This is available on Rainbow ward.

Chemotherapy at Home

Oral Chemotherapy

As part of your child's treatment you may be required to give oral (tablets or liquid) chemotherapy at home. If your child has Leukaemia then the dose is usually coordinated by the Leukaemia Nurse Specialist and depends on your child's blood results.

KidzMedz Cymru is a project designed to teach paediatric patients over the age of five how to safely swallow tablets and capsules. This could be useful if your child struggles with liquid medications.

Ensure you have gloves, a purple bin and syringes or pots to take home with you. Please dispose of any chemotherapy related items in the purple bin and return the bin to the hospital when full. Ensure the oral chemotherapy and purple bin is stored in a safe place in your home away from other children and pets.

Please also **wear disposable gloves** when changing nappies and handling your child's body waste (urine, vomit and poo) as traces of chemotherapy will be in your child's waste for up to 7 days after chemotherapy.

Storage of intravenous (IV) chemotherapy at home - As part of your child's treatment you may be asked to take home and store IV chemotherapy so that your child's POONS can administer this at home. This must be stored in the container provided by Rainbow Ward in your fridge. It must be away from other food items in the fridge and the fridge must be in good working order (temperature between 2-8 °C).

The Rainbow Team

Manager – Sian Jones

Deputy Ward Manager – Michelle McLachlan

Rainbow nurses – provide care on the ward and day beds unit, supported by health care support workers.

Clinical Nurse Specialist/Key Worker – provide expert knowledge and support and coordinate care. All questions must come through your key worker. Consultants will not reply to emails/telephone calls directly.

POONS – The POONS are a team of specialist oncology nurses who will support you and your child at home throughout treatment. They carry out line cares, blood sampling and some chemotherapy.

Advanced Nurse Practitioner – Provide expert clinical knowledge and see patients on Rainbow ward, Day beds and Rocket.

Medical staff – Your child will have their own named consultant. However, there will always be one consultant in charge of the ward during the day. Junior doctors provide care on the ward/daybeds & Rocket.

Research Nurses - Provide expert knowledge and support for the many clinical trials taking place, co-ordinating sampling and visits.

Palliative Care team – provide support and symptom management advice. Your child may require this team for advice on managing pain.

LATCH - Welsh children's cancer charity. Supports children and their families receiving treatment for cancer at the Children's Hospital for Wales

Cancer Care is **complex** and there will be many people involved in your child's care. These may include; social workers, psychology support, other medical teams, dietician, physio, play specialists, pharmacy, speech and language specialists, hospital teachers etc.

Other sources of information

Contact Magazine – a free magazine released quarterly aimed at families of children and young people with cancer. A great source for information and can ease the feeling of isolation. Available online from the CCLG website.

Recommended websites:

www.cclg.org.uk

www.clicsargent.org.uk

www.cancerresearch.org

www.latchwales.org

www.macmillan.org.uk

www.thebraintumourcharity.org

This booklet was written by Julie Barnett (Paediatric Oncology/ Haematology Advanced Nurse Practitioner), Rainbow Ward, Children's Hospital for Wales.

In compiling the information, input from parents and colleagues has been included.

Originally written in June 2015. Updated in 2018 and 2023 by Julie Barnett (ANP) & Claire Lawson (Chemotherapy CNS). Leaflet kindly funded by LATCH.

Art work done by Mia, aged 15 years.