

SIOP PODC Supportive Care Education

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Recording Link at www.cure4kids.org:

https://www.cure4kids.org/ums/home/conference_rooms/enter.php?room=p55smgdpkzn

Educating the caregivers of childhood cancer patients

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Despite availability of effective anti-cancer treatment EFS can be low in developing countries

Aim

- Look at root causes of the high mortality
- See how education of caregivers can reduce the morbidity and mortality associated with cancer treatment
- Care givers include doctors, nurses and parents
- Main focus on education and support of parents

UKALL 2003 – Outcome by Immunophenotype

	% 5-yr (se)
Event Free Survival	
B -lineage	89.2 (0.8)
T -lineage	84.1 (2.4)
Relapse Risk	
B-lineage	7.6 (0.8)
T-lineage	12.4 (2.3)
Death in remission	
B-lineage	2.6 (0.4)
T-lineage	3.2 (1.1)
Overall survival	
B-lineage	92.7 (0.7)
T-lineage	88.6 (2.1)

MRC AML10/12/15 Paediatrics: All Patients

Endpoint @ 5 years	AML10	AML12	AML 15
Induction Death	4%	4%	4.7%
Resistant Disease	4%	4%	4.2%
Complete Remission	92%	92%	91%
Death in Complete Remission	11%	6%	7%
Disease Free Survival	52%	61%	60%
Event Free Survival	48%	56%	54%
Overall Survival	57%	66%	74%
Relapse Risk	41%	35%	36%

Extent of problem

- SKM – 2011. Causes of mortality in children with ALL treated between 2001-2005.
- 304 pts , 74 (24%) died.
- Induction 39/74(52%), 33(44.5%) in first remission and 2(2.8%) before start of therapy

Causes of death

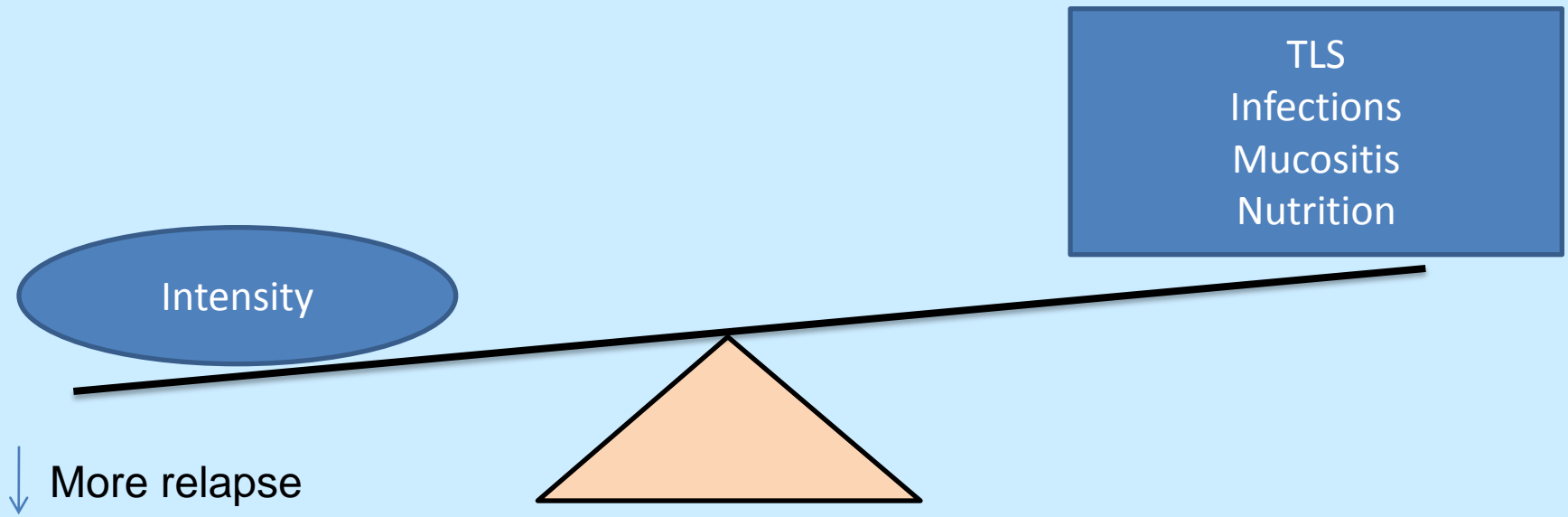
- Infection +/- other factors 63/74(85%)
 - Septicemia 37/63(58.7%)
 - Pulmonary 44/63 (69%)
 - Gastrointestinal 8/63(12.6%)
- 8(10.8%) haemorrhage
- 3(4%) chemotherapy induced toxicity

Asim M, Zaidi A et al J Pak Med assoc 2011; 61(7):666-70.

ALL experience at AKU

- 121 children diagnosed between Jan 1997 – Dec 2006
- 86(87%) had precursor B and 13(13%) T cell
- 15(11.6%) were lost to follow-up
- 20(16.5%) died with infection being the most common cause of death

Mushtaq N, Fadoo Z et al J Pak Med Assoc 2013; 63(11):1399 - 404



Other causes of morbidity in ALL pts

Risk Group	All patients (%)	Reg A (%)	Reg B(%)	Reg C (%)	p – value (heterogeneity)	p-value (St/int v high)
<i>Any infection</i>	307 (13.3)	134 (11.1)	98 (17.5)	75 (14.0)	0.001	0.63
<i>Fungal infection</i>	81 (3.5)	25 (2.1)	35 (6.2)	21 (3.9)	<0.0001	0.58
<i>Encephalopathy (excluding seizure)</i>	164 (7.1)	43 (3.6)	58 (10.4)	63 (11.7)	<0.0001	<0.0001
<i>Asparaginase Hypersensitivity</i>	47 (2.0)	4 (0.3)	3 (0.5)	40 (7.4)	<0.0001	<0.0001
<i>Pancreatitis</i>	33 (1.4)	9 (0.7)	8 (1.4)	16 (3.0)	0.0015	0.0006
<i>Osteonecrosis</i>	88 (3.8)	9 (0.7)	52 (9.3)	27 (5.0)	<0.0001	0.097
<i>Thrombosis</i>	51 (2.2)	20 (1.7)	15 (2.7)	16 (3.0)	0.16	0.17
<i>CNS Thrombosis</i>	31 (1.3)	12 (1.0)	10 (1.8)	9 (1.67)	0.31	0.45
<i>Number in risk groups</i>	2300	1203	560	537		

Provision for supportive care

- Any money spent on training/supporting parents will save lives
- Have a separate budget including manpower for training and support of staff and parents
- Each hospital has to find its own solution
- Will reduce mortality and LAMA rate
- Financial support of families
- Psychological support of families

What do we need to educate parents about

- Risk of infection and how to avoid them
- Personal and environmental hygiene
- Dietary advice and food hygiene
- Vaccinations – any seasonal vaccination e.g flu, typhoid vaccinations
- Measures against particular infections – malaria, Dengue fever, chicken-pox
- Education regarding harmful myths and beliefs

Establish behaviour patterns in hospital

- Availability of soap and water – wash hand after toilet and before eating
- Teach parents to take soap and bottle of water with them if travelling
- Make sure patient and attendants bathe daily
- Daily change of clothes
- Advise to take clean drinking water with them when travelling
- Importance of clean water
- Availability of washing machines or places for washing clothes and utensils

Nutrition

- Clean wholesome freshly cooked cheap food
- Seasonal fruit and vegetables just as good as expensive apples, grapes etc
- If eating outside eat hot freshly cooked food
- Use milk (lassi milk shakes), vegetable or fruit juices and yoghurts if child not eating solid food.
- Use nasogastric tubes early if the child is not eating

LAMA

Left against medical advice

- Look at data from the last 5 years
- What were the reasons for patients leaving
- How many patients went to other hospitals??
- How many patients tried alternative medicines??
- How many patients came back???
- Develop a strategy for patients leaving without finishing treatment

Usual reasons

- Patients live too far away
- Father sole bread earner
- Cost of living too high in the big hospitals
- Lack of education – think child is cured when they are in remission
- Belief in faith healers and alternative medicine

Have a strategy to prevent 'LAMA'

- Establish a fund for supportive care
- A social worker, nurse and doctor team should be in-charge of the strategy
- A detailed family history should be taken on admission including no of children, parental education, income, family support and place of residence

Some strategies

- Live far away
- Explain the whole treatment including intensity and length of treatment
- Explain disease will come back if they don't complete treatment
- Better not to start if they are not going to complete treatment
- Work with parents – explore possibility of intensive treatment being given in the centre and milder treatment closer to home.

....Contd

Dad or mum sole bread earner

- See if one parent and another family member can stay with the family
- See if food and clothing can be provided (a clothes bank can be developed with clothes being collected for this purpose)

....Contd

Belief in faith healers and alternative medicine

- Educate the families from Day 1. If they are adamant (and treatment harmless) ask them to have the treatment alongside chemotherapy

Treat side effects optimally

- Adequate pain control must
- Treat nausea and vomiting adequately
- Psychological support of patient and family

Prospective monitoring of patients who LAMA

- There should be a register recording names of all the patients who LAMA
- The reason why they leave, family circumstances and distance from hospital should also be recorded.
- A 6 monthly review of patients who LAMA
- Discuss if something could have done to prevent patients leaving

Arrangements prior to sending home

- Find out about home situation
- How many children, job state of cleanliness
- How far are they from the cancer hospital
- How far are they from the local hospital

Contribution of local shared care centres

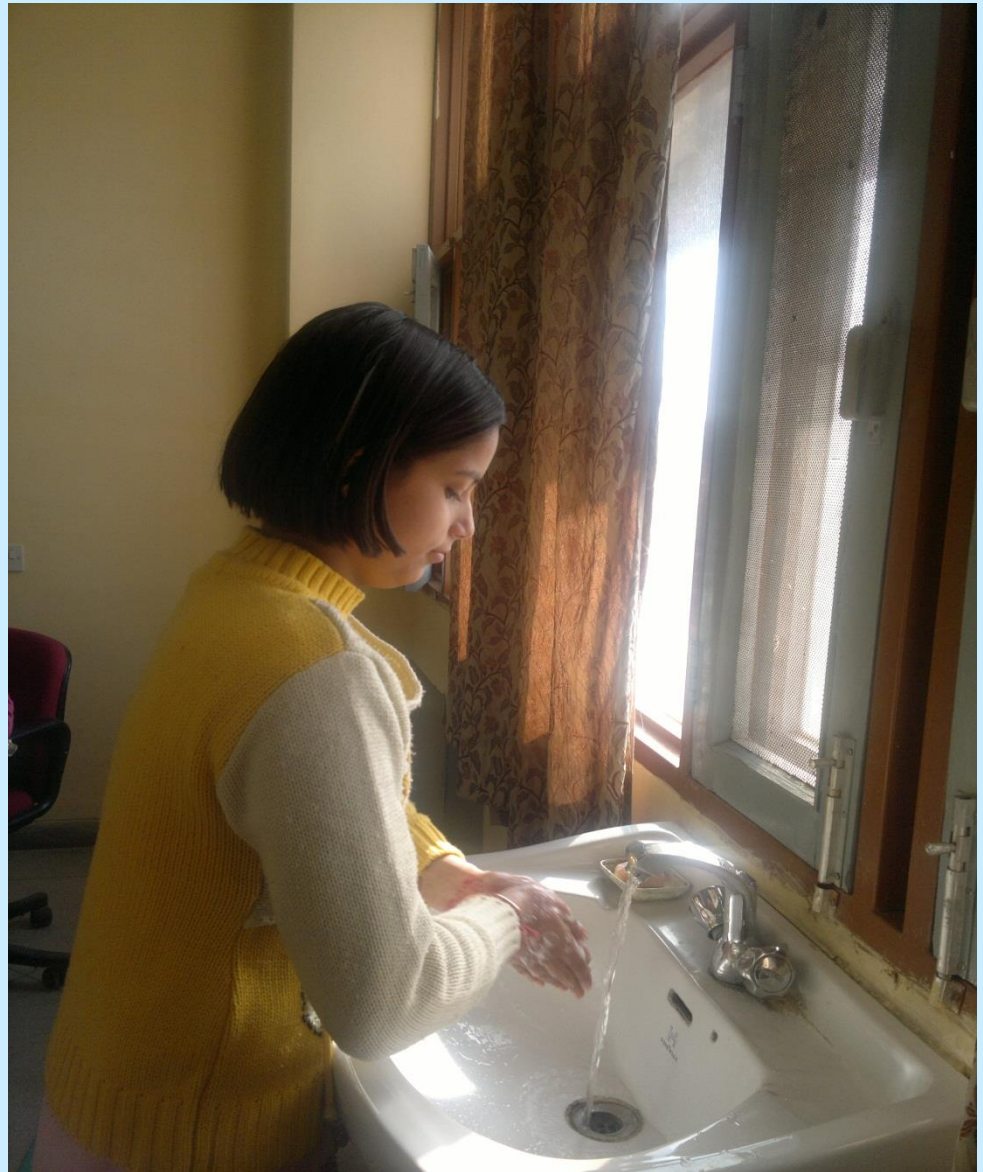
- Management of infections
- Administration of blood products
- Administration of simple chemo
- Good training of junior doctors and nurses across centres
- Follow same protocol and guidelines
- Good communication between centres

How to train parents

- Set the standards by example in hospital
- Nurse training sessions for parents one to one depending on family education and understanding
- Use translators if family speaks regional languages and dialects
- Group information giving sessions. Use of recorded sessions supervised by health assistants may be used
- Availability of leaflets in local languages
- Availability of patient held records
- Use of standard supportive care protocol across all sites treating patient

Posters with health messages

- Messages should be simple quick to read
- Visual images are often more powerful than words
- They are also a constant reminder that simple things like hand washing can save lives
- Use posters methodically



Information and training staff & patients

Supportive care
information for parents

- What number to call
- Nutrition
- Febrile neutropenia
- Handwashing
- Record of blood counts

**Supportive care
guidelines for
doctors and nurses**

CCLG PODC leaflets

www.cclg.org.uk

<http://www.cclg.org.uk/treatment-research/caring-for-a-child-with-cancer-in-developing-countries>

- Urdu
- English
- Arabic
- Hindi
- **Punjabi – (sanskrit script)**
- Kannada
- Nepalese



Children's Cancer & Leukaemia Group
Paediatric Oncology in Developing Countries

Caring for a child with cancer

Introduction

This leaflet provides basic information and practical advice to help you care for your child when they are having treatment for cancer, to give them the best chance of cure. Treatment may include chemotherapy, radiotherapy or surgery or a combination of the above. Most patients have chemotherapy that will be discussed in greater detail.

The leaflet addresses:

- Common side effects of treatment
- How to prevent side effects
- Frequently asked questions about treatment

What is chemotherapy?

Chemotherapy is treatment with drugs that can be given in the vein or by mouth. The duration of treatment can vary from 2 months to over 3 years depending on the type of cancer. While chemotherapy is very effective in curing cancer it also produces a number of side effects, some of which can be life threatening if not treated promptly and effectively.

Common side effects of chemotherapy

The main side effect of chemotherapy is that it suppresses the body's ability to fight diseases and will put your child at risk of developing infections. This means your child can easily get coughs, colds, diarrhea, skin infections, and other more serious infections. They are also more likely to catch other illnesses that may be more prevalent in your area like malaria, typhoid or hepatitis.

Your doctor will have mentioned side effects from individual medicines but the common side effects are:

- Repeated infections
- Painful mouth ulcers and/or abdominal pain
- Nausea and/or vomiting requiring anti-sickness drugs
- Difficulty eating leading to poor appetite/diet and weight loss

Side effects of steroid medication?

Steroids (such as Dexamethasone or Prednisolone) are commonly used for the treatment of leukaemia and lymphoma. The side effects include weight gain, tummy pain and behavioural changes. Your child may want considerably more food than usual, less food or completely different food. Most children feel very hungry and demand a certain type of food. Your child may be emotional, moody or irritable. High blood pressure, increased blood sugars and muscle weakness are other known side effects. While the side effects may be worrying they will disappear when the steroids are stopped.

What should I do if my child misses a dose or vomits his medicine?

For drugs to have the maximum effect, it is essential to give the correct medicine at the correct dose and at the correct time. However, if your child forgets to take his medicine, inform your doctor. Do not double the next dose. If your child vomits the medicine do not give another dose as the amount absorbed prior to vomiting cannot be calculated.

What foods should I give my child?

- All kinds of fresh home-cooked food is recommended.
- Do not reheat old food.
- Only give your child fruit that can be peeled i.e. bananas, melons & oranges.
- Fish, chicken and eggs are fine if your child likes them. These should be cooked thoroughly and served fresh.
- Avoid take away food or food from vendors. This includes ice creams and sweets. Your child may have crisps or packaged biscuits, chocolates or candies.
- Boil drinking water for 20 minutes and cool in the same container. Bottled drinking water is fine. A water filter should only be used if it is changed frequently as recommended.

REMEMBER UNCLEAN WATER CAN CAUSE SERIOUS INFECTIONS.

Can my child go to school?

After the intensive phases of therapy your child should go to school if your doctor thinks your child is well enough.

Who can my child play with?

Your child can play with brothers and sisters. Your child can also play with friends if the friends don't have an infection or cold. Cancer is not infectious. Brothers and sisters or friends will not get cancer from eating/playing with the affected child.

CANCER IS NOT CONTAGIOUS AND CANNOT SPREAD BY CONTACT

Contact Numbers

Doctor:
Main Hospital:
Ward:
Outpatients:
Nurse in charge:
Local Hospital:
Lab for blood counts:

This leaflet was written by the CCLG Paediatric Oncology in Developing Countries (PODC) Group, a group of consultants, doctors and nurses involved in treating children with cancer across the world. It was produced in conjunction with the Children's Cancer and Leukaemia Group (CCLG) Publications Committee who have produced a number of information leaflets to help parents of children with cancer in the UK. Email contactus@port.uk.com for more information.

This leaflet is for general information only. It is important to remember that your doctor understands your child's medical needs and history so please follow their instructions.

How to prevent the main side effects and serious infections

Regular blood tests

Your child will have regular blood tests that will show you and the doctors if your child is at risk of developing an infection or if the dose of chemotherapy needs adjustment.

The bone marrow is the 'factory' that produces the different types of blood cells, each of which have a different job to do in the body. Chemotherapy kills cancer cells, but as a side effect it also suppresses the bone marrow that affects the blood count.

There are 3 main types of blood cells that the bone marrow makes:

- Red blood cells (containing haemoglobin) carry oxygen around the body and give your child energy. If the level is low, this is called anemia; your child may be pale and tired, and sometimes may need a blood transfusion.
- White blood cells are the 'soldiers' that fight infections. There are different types of white blood cells, but the most important ones are called neutrophils. When the level of neutrophils drops below 1000, this is called neutropenia and your child is at higher risk of serious infection.
- Platelets help the blood to clot properly. If the levels are too low your child may develop bruises, red spots or bleeding such as nose bleeds or bleeding gums. Your child may need a platelet transfusion from time to time.

It is important to have the blood count checked regularly because the dose of medicine your child is given is adjusted according to these blood count results. Sometimes the medicine needs to be stopped for a period of time. For other cancers the blood counts will inform the doctors whether your child is ready to receive the next treatment.

Management of Infections

If your child has a neutrophil count less than 1000 AND has a temperature it is called febrile neutropenia. This can occur quite frequently without serious consequences but can also be a sign of serious infection that can be fatal in a matter of hours. This is why you MUST ring your doctor or go to the doctor immediately if your child has a fever. It is likely that your child will need to be started on intravenous antibiotics (drugs that fight infections).

If your child has a temperature, do not give medicine (such as Calpol, paracetamol, ibuprofen, and Brufen) to bring down the temperature until your child has been seen by the doctor as this can hide the infection without actually treating it. This means that your child could get seriously ill without anybody realising it. If you have to travel far your doctor may arrange for you to have urgent care closer to where you live to prevent the infection from becoming serious.

SEEK MEDICAL ADVICE IMMEDIATELY IF YOUR CHILD HAS A FEVER OR IS UNWELL WHATEVER THE BLOOD COUNT.

Maintaining daily hygiene to avoid infections

Maintaining good daily hygiene is essential to help avoid infections. The following should be adhered to at all times:

- Wash hands thoroughly before giving any medicine or checking any bandages or wounds. Your doctor/ nurse will explain the best way to wash your hands properly.
- Wash your hands thoroughly before cooking or preparing any food.
- Where possible a daily bath, clean clothes and good mouth hygiene are very important. Avoid playing in dirty surroundings. Wash your hands before eating and after going to the toilet.

- Freshly cooked, clean simple, food should be provided.
- Clean water supply is also very important.

Avoiding mouth infections:

Due to the way chemotherapy works your child's mouth might become sore and painful and/ or develop mouth ulcers that can become infected. You can help reduce the chance of this happening by making sure the teeth are cleaned properly and thoroughly at least twice a day, with a soft tooth brush. If you are provided with anti bacterial spray or mouthwash and sponges please use them as well as ensuring teeth are brushed twice a day.

Avoid contact with contagious diseases

If your child is going to a school or nursery you should tell them they must inform you if your child comes into contact with anyone that has or develops chicken pox or other infectious illnesses.

- Avoid contact with friends and relatives who have colds, open sores, diarrhea or other infectious illnesses.
- Children undergoing cancer chemotherapy may develop life threatening complications if they have chicken pox or measles. Your doctor will usually enquire at the very beginning of treatment whether or not your child has had chicken pox or has received the chicken pox and measles vaccines. If your child comes in contact with anyone with either of these conditions, you must contact the hospital urgently so that preventive measures can be taken.
- During the malaria season use mosquito netting and insect repellents to avoid getting malaria.
- Both malaria and dengue fever can be prevented by keeping your surroundings clean and draining any stagnant water.
- If the water supply in your area is not safe, give your child only boiled, or filtered water (remember to change filter regularly) to prevent waterborne infections like diarrhea.

Contact with animals

Animals can be a source of infection if they are not looked after properly and kept clean. If your family has a pet you have looked after for a long time, you should keep it. However hands must be washed after contact with pets to avoid infections.

Where possible, contact should be avoided with lizards, farm animals, wild or stray animals and birds.

Don't introduce a cat or dog to the house if you don't already have one.

If living on a farm and contact or working with animals can't be avoided, clothes must be changed and hands washed thoroughly after contact.

Frequently asked questions about treatment

Why is it important to complete treatment even when my child is in remission and well?
Cancer treatment is given to make sure all cancer cells are killed. If treatment is stopped too soon, the cancer may come back and will then be more difficult to treat. Even if it causes side effects, treatment needs to continue to give your child the maximum chance of cure. However, please discuss this with your doctor because sometimes treatment needs to be modified if side effects are severe.



یہ کتابچہ بنیادی معلومات فراہم کرتا ہے۔ آپ کا ڈاکٹر آپ کے بچے کو معرطہ طریقے سے بہاتا ہے تاکہ اسی کی بطنی جوتی تبدیل ہو کر عمل کریں۔

ایم ڈائیمس کے طریقے اور دیگر مضر اثرات سے بچاؤ کی تر

پے کے ساتھ بائسکی سے خون کے قسمت کیے ہاتھ میں جن کے مطابق کیمو تھراپی کی مقدار کم یا زیادہ کی جاتی ہے۔

ہیون میو (ہاؤس کا گواہ) خون ہانے کی فیکٹری ہوتا ہے۔ خون کے قسمت بننے پر کارنا ہے یہ نکلنے جسم کے قسمت کام سر انجام دیتے ہیں۔ کیمو تھراپی جہاں کھنسر کے طریقے کو کم کرتی ہے وہاں یہ ہیون میو کو بھی مٹا کرتی ہے۔

ہیون میو میں طرح کے نکلنے پیدا کرتا ہے۔

۱۔ خون کے سرخ نکلنے جسم کو آکسیجن اور توانائی مینا کرتے ہیں ان کی مقدار کم ہونے کو ایمیا (Anemia) کہتے ہیں۔ ایسے پے کا رنگت دیکھا جاتا ہے اور وہ ہلکی خفک ہوتا ہے۔ ایسی صورت میں خون بھی گھٹا ہوا ہوتا ہے۔

۲۔ خون کے سفید نکلے ڈائیمس کے نکلے سے ان کی قسمت اقام ہوتی ہیں جن میں سب سے اہم نیوٹروفیلز (Neutrophils) ہیں۔ اگر ان کی مقدار ۱۰۰۰ سے کم ہو تو اس کو (Neutropenia) کہا جاتا ہے۔ ایسے پے میں ڈائیمس کے نکلے کا خطرہ زیادہ ہوتا ہے۔

۳۔ پلیٹلیٹس (Platelets) خون ہانے میں مددگار ہوتے ہیں ان کی کمی سے جسم پر نیل یا سرخ لٹھان بن سکتے ہیں اور ناک یا موزوں سے خون بہہ سکتا ہے۔

آپکے کچھ کثرت ضرورت پلیٹلٹ گھٹا پڑ سکتے ہیں۔

خون کے ان ٹھیک کی مقدار کو قسمت کے ذریعے بائسکی سے ویک کرنا بہت ضروری ہے تاکہ کیمو تھراپی کی مقدار میں توازن رکھا جاسکے۔

بعض اوقات دوائی کو فوجی طور کے لئے بند ہی کرنا پڑتا ہے۔

آپ اس کا پے کی پلاٹ پر موجود پلاٹ میں ان ٹھیک کے نتائج کا انداز کر سکتے ہیں۔

ڈائیمس (Infection) کے نکلے کا علاج

اگر پے کے نیوٹروفیلز ۱۰۰۰ سے کم ہیں اور اسے تیار ہو تو اسے Febrile Neutropenia کہتے ہیں۔ آپ کا پے ایسی صورت حال سے بچاؤ دوا ہر ہوتا ہے جن میں سے کچھ Infection بہت سے سنگین نتائج کا حامل بھی ہو سکتے ہیں۔

اسلئے آپ کو فورا اپنے ڈاکٹر سے رابطہ کرنا چاہئے تاکہ جو سکتا ہے کہ پے کو طبیکی ایجنٹ ٹھیک کی ضرورت ہو۔

اگر آپ کے پے کو تیار ہو تو اسے تیار کر کے دوائی دینی چاہئے یہ اسٹامول (Paracetamol یا Brufen)، اس وقت تک نہ دیں جب تک ڈاکٹر پے کو دیکر نہ لے تاکہ ایسا کرنے سے انفیکشن کی علامات بہت بڑھ جاتی ہیں۔

اگر آپ کو سڑک یا جو تو آپ قریبی ہسپتال میں پے کی دیکھ بھال کا انتظام کر سکتے ہیں۔

سب سے اہم نظام یہ ہے کہ اگر آپ کے پے کی طبیعت قراب ہو یا تیار ہو تو قریبی طبی اور ادوا حامل پکے ہوا بیمار دیکھ کر بھی ہو۔

ڈائیمس سے بچاؤ کیلئے سفالی کا انتظام

انفیکشن سے بچنے کے لئے سفالی تھراپی کا خاص خیال لازم ہے۔ مددگار ذیل اصولوں پر ہمیشہ عمل کیجئے۔

۱۔ کھانا یا دوائی کھانے سے پہلے یا کسی دھڑکی مرہ میں کرنے سے پہلے ایسی طرح پاتر دھوئیں۔ آپ کا ڈاکٹر یا سز ایچ پاتر دھونے کا صحیح طریقہ بتائیں گے۔

۲۔ کھانا پکانے سے پہلے پاتر دھوا بہت ضروری ہے۔

۳۔ دروازہ نہیں، صاف سطرے پیرے ہیں اور دھواں اور مڑکی سفالی کا خاص خیال رکھیں۔

۴۔ گتے یا حامل میں کھینچنے سے پرہیز کریں۔ کھانا کھانے سے پہلے اور غسل لانے سے واپسی پر ایسی طرح پاتر دھوئیں۔

۵۔ تیار اور ایسی طرح کی جلی اور سادہ خوراک کھائیں۔

۶۔ صاف پانی کی فراہمی ہے بہ اہم ہے۔

مڑکی بھاریوں سے بچاؤ

کیمو تھراپی سے مڑکی میں درد ہو سکتا ہے اور کھیت دہانے میں سکتے ہیں جن میں انفیکشن ہو سکتا ہے۔ دھواں کو دھواں میں کم دھواں دوسرے نرم روش سے صاف کرنے سے اس کا امکان دور سے کم ہو سکتا ہے۔ ایسی صورت میں ایسی ٹیکسٹیل سپرے یا مازخوش استعمال کرنے سے بہت مدد مل سکتی ہے۔

صحت کی بھاریوں سے بچاؤ

- سکل یا دوسری بائیسال بھی کیلئے ضروری ہے کہ اگر وہ کسی ایسے پے کے قریب ہائیں جس کو فورو، آکادہ یا کوئی دوسری مٹھی یا ہلکی بھاری ہے تو آپ کو فورا بچا کر لیا جائے۔
- ایسے دوست یا رشتہ دار جنھیں کھانسی، زکام یا سینہ یا کھلی اور مٹھی بھاری سے تھوڑے آپکے پے سے دور ہیں۔
- کیمو تھراپی کے لئے واپس کیمو فورا یا آکادہ یا جو ہانا بہت خطرناک ثابت ہو سکتا ہے۔ علاج کے شروع میں آپ کے ڈاکٹر آپ سے ان بھاریوں سے بچاؤ کے نکلے کے بارے میں پوچھیں گے۔
- اگر آپ کا کچھ ایسی بھاری ہے کسی مرہ میں کے قریب لیا ہو تو اپنے ڈاکٹر سے قریبی رابطہ کیجئے تاکہ استقامتی تھراپی کی جاسکے۔
- لمبیا کے موسم میں پھر سے پے کیلئے بھلی اور پھر لمبیا دوائی کا استعمال کریں۔
- فیرا اور ڈنگلی تیار کرنا پے اہل کو صاف رکھنے اور پانی کی لکھی سے روکا جاسکتا ہے۔
- اگر آپ کے علاقے میں پین کا صاف پانی میا نہ ہو تو اپنے پے کو لگا جیالینڈر شرا پانی پائیں تاکہ پانی کے ذریعے جھینے والی بھاریوں مٹا سہاں، سینہ وغیرہ سے بچا جاسکے

ہاتھوں کے ساتھ رابطہ

- ہاتھ کو کر صاف عسرا نہ کرنا بہت ضروری ہے جھینچے کا سبب ہوتے ہیں۔ اگر آپ کے گھر میں کھلی یا تھو ہاتھ پہلے سے موجود ہے تو آپ اس کو دھو سکتے ہیں لیکن انھیں ہاتھ لگانے کے بعد بھی طرح پاتر دھوا ضروری ہے۔
- ہاتھ تکٹ مکھن ہو مچھلی، قارم کے ہاتھ اور آوارہ ہاتھوں سے نہیں۔
- اگر آپ کے پاس پہلے سے کوئی یا تھو ہاتھ نہیں ہے تو کوئی اور ہاتھ گھر میں نہ لائیں۔
- اگر آپ گھٹن میں رستے ہیں اور ہاتھوں کے ساتھ رستے یا ان کے ساتھ کام کرنے سے گریز نہیں کیا جاسکتا تو ایسا کرنے کے بعد اپنے پیرے تھوہل کریں اور بھی طرح پاتر دھوئیں۔

طرح کے بارے میں ایچ پی سی کے حالات

اگر کیمو راجی صحت یاب ہو گیا ہے تو بھی طرح کی مہیا دھاری کرنا نہیں ضروری ہے۔؟

کھنسر کے علاج میں اس بات کو بھی بھانا بہت ضروری ہے کہ کھنسر کے تمام نکلے مر چکے ہیں۔ اگر علاج مدد دیا جائے تو کھنسر واپس آسکتا ہے اور ایسی صورت میں علاج زیادہ مشکل ہو جاتا ہے اسلئے اگر اس کے کچھ مضر اثرات بھی ہیں تو بھی کھنسر سے مکمل نجات کیلئے طرح بادی رکھا ضروری ہے تاکہ مضر اثرات بہت شدید نہیں ہوں تو اپنے ڈاکٹر سے رابطہ کریں تاکہ طرح میں کھلی جہلی کی جاسکے۔

۱۔ اگر میسر ہے کھلی میں دوائی میں ماتھ بھانے یا دھوا کرانے کے بعد اپنی کر دے تو کیا کرنا چاہیے؟

طرح کے معزز اثر کے لئے ضروری ہے کہ صبح دوائی صبح تیار ہیں اور صبح وقت پر ہی ہانے تاکہ اگر آپ کا پے دوائی لیا جامل ہانے تو اپنے ڈاکٹر کو مطلع کریں۔

اچھی خوراک کو دیکھا نہ کریں۔

اگر آپ کا پے الٹی کر دے تو خوراک دوبارہ مدت میں کیجئے کہ سے پہلے مدد سے مہذب ہو جائے ولی مقدار کا دوا نہیں لگایا جاسکتا۔



The Urdu leaflet being used at the
Children's hospital Lahore
Pakistan

Importance of audit and research

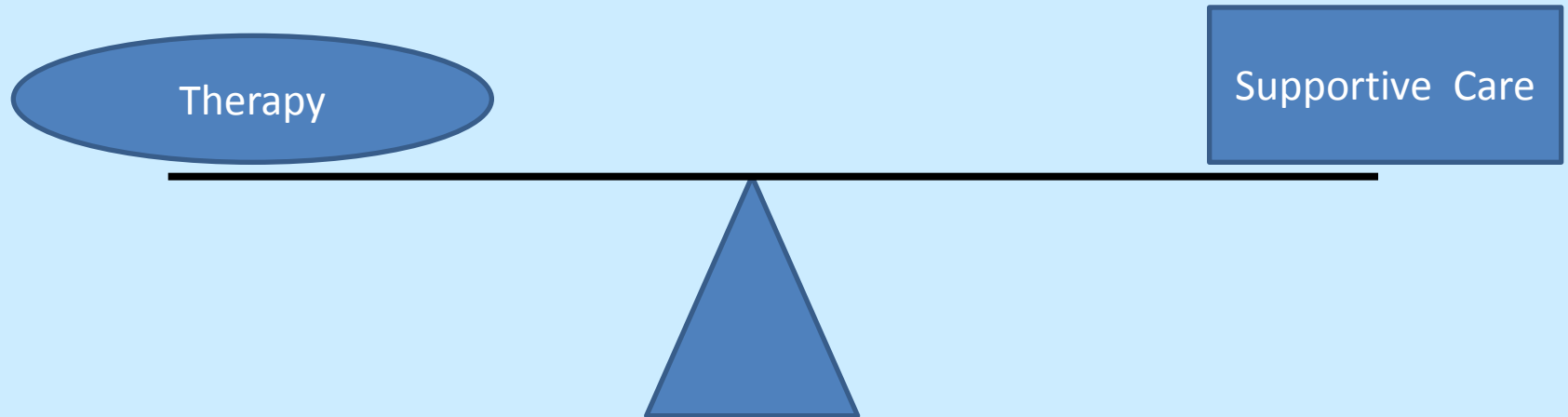
- At the start of rotation individual registrars should be made in-charge of various aspects of supportive care including
- Assessing quality of information giving – can be done by brief patient/parent questionnaire
- Assessing LAMA rates and reasons
- Level of personal hygiene of patients and parents
- Were all patients given leaflets
- Quality of discharge – discharge summaries, establishment of local care

Quality improvement forums

- The data collected should then be presented 6 monthly.
- Based on the findings practices should be changed to prevent the same problems from happening the futures
- Establishment of closer links with local hospitals to improve local care being given to patients.

First do no harm....

Recognition that we need to have a robust constantly monitored pathway involving doctors, nurses, psychologists, social workers, dieticians and others that support the patients and parents through this difficult journey



Key points

- Have well defined roles for different members of the team
- Take detailed family histories and try and sort out problems before the patient gets to point of 'LAMA'
- Be proactive about giving information.
- Establish routines in hospital
- Constantly assess and improve.