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**Appendix A: Lesson plans for the leukaemia intervention**

Workshop One

The structure of the human body and the effects of chemotherapy on it. Side effects which they may have had.

Introductions

Introduce the children to each other.

Introduce the students to the way the workshops are run:

Exploratory activity: initial activity where children are able to explore objects followed by explanation

 Activity one: to consolidate learning

 Activity two: to consolidate learning

1. Exploratory activity

Explore the body models: skeleton and organ models. See if they can put the bones and organs back together. There will also be a table with books for reference.

Organs:

Can they find the organs and match them to their functions:

The heart

The lungs

The stomach

The liver

The intestines

The brain

The kidneys

Skeletons:

What are the functions of our bones? Structure, movement, protect organs

Can they identify these bones:

The skull

The pelvis

The ribcage

The femur

The humerus

The spine

1. Activity One: Bowling game

Chemotherapy: this is how doctors treat leukaemia. It involves using a combination of drugs to kill the leukaemia cells. First they use the drugs to wipe out the leukaemia cells and then they use drugs to make sure the leukaemia cells do not come back.

Purpose of the activity: to demonstrate that the drugs which the doctors use to kill the leukaemia cells also affect other parts of the body.

This is why they have unpleasant side effects:

Nausea/vomiting

Mouth ulcers

Skin problems

Loss of appetite/weight (although steroids can lead to increased weight)

Hair loss

Infections

Bruising

Tiredness

Diarrhoea

Kidney damage

This is also why they should lead healthy lifestyles in the future: to reduce risks to their body from the damage of chemotherapy.

The bowling pins are labelled with:

The heart

Blood cells: healthy white blood cells and red blood cells

The stomach

The liver

The intestines

The brain

The kidneys

Leukaemia cells

Hair

Skin

The balls represent the different drugs.

Names: can use names if the children use them or just say chemotherapy

Examples of drug names:

* Vincristine (Oncovin)
* Daunorubicin, also known as daunomycin (Cerubidine)
* Doxorubicin (Adriamycin)
* Cytarabine, also known as cytosine arabinoside or ara-C (Cytosar)
* L-asparaginase (Elspar), PEG-L-asparaginase (pegaspargase, Oncaspar)
* Etoposide (VePesid, others)
* Teniposide (Vumon)
* 6-mercaptopurine (Purinethol)
* 6-thioguanine
* Methotrexate
* Mitoxantrone
* Cyclophosphamide (Cytoxan)
* Prednisone (numerous brand names) - steroid
* Dexamethasone (Decadron, others) - steroid

Each child has two goes at bowling the chemotherapy drugs: score +10 for knocking down the leukaemia cells and -1 for each side effect.

While playing the game children can discuss whether they have had any side effects and how they reduce their effects:

Examples:

Change diet

Rest

Anti-sickness medication eg. Steroids used to increase appetite and reduce sickness.

Avoid picking up infections

What happens if the initial treatment does not get rid of all the leukaemia cells:

Use stronger drugs (e.g. bigger ball, but this can cause more side effects)

Stem cell transplant: use chemotherapy to get rid of the cells in the bone marrow which make blood and replace with new cells

1. Activity Two: Changes in physical appearance

Chemotherapy causes hair loss, scars, changes in body size, skin problems etc. so it can make people feel differently about themselves. However, these changes are temporary.

People often change their appearance. This activity uses cards, pictures and art materials to explore ways of changing appearance. Examples:

Hairstyles

Hats/caps

Hair colour

Facial hair

Clothes

Make-up

Jewellery

Glasses

Decorate their face pictures. Can add hair/hats/glasses etc. or draw on their own.

During the activity, children can talk about how their appearance changed during chemotherapy and how they cope(d) with this, if they want to. However, they are not asked to.

Workshop Two

The circulatory system: examine the models of the heart and body.

Model of torso

Model of heart

Pumping heart model

Stethoscopes

Exploratory activity

1. Introduce the session. The heart and the circulatory system. What is leukaemia and how does it affect the blood and cause the symptoms of leukaemia?

The heart

1. Where is the heart and what does it do? Where is it on the model and in the body? How big is it? If they look at the model of the heart what does it look like?
2. Listen to hearts with the stethoscope. What can they hear? The noise is the valves closing. Two sets of valves. How many times does their heart beat a minute. This is the pulse rate. How do you make your heart beat faster?
3. Your heart is very important. How do you keep it healthy? Diet and exercise.

The circulatory system

1. Show how blood travels through the heart and round the body. It gets pumped to the lungs first. Do they know why? Then it carries the oxygen around the body so the body can function. The blood then goes back to the heart and gets pumped back to the lungs for more oxygen. Could imagine it as being like a train track delivering things round the body.
2. Demonstrate the pumping heart model.

Activity Two: ‘Put it together’ blood activity

1. What does the blood do? Why do we need it? To transport oxygen and other nutrients. To keep the body temperature at the right level. To send messages around the body (hormonal).
2. What is the blood made from. Look at the models of the constituents of the blood: red blood cells, white blood cells (lymphocytes and granulocytes), platelets (activated and non-activated) and plasma. Match them to their functions. Put the blood back together in the tube.

Leukaemia

1. For each of the cells think what might happen if they didn’t have those cells:

 Eg. Red blood cell- low oxygen/energy= anaemia

 WBC- infections, wbc also fight cancer, lymphocytes reduce immunity

After chemotherapy common to lose immunity and may get eg. Chickenpox again.

Platelets- bleeding because blood wouldn’t clot. Bruising.

1. Do they know what leukaemia is? These are the symptoms of leukaemia because the normal blood cells can’t be produced in large numbers.
2. Demonstrate the proliferation of blasts using a model. Then remove the blasts to demonstrate the function of chemotherapy.

Activity Two: Spot the difference:

1. Look at pictures of normal and leukaemic blood. Can they guess which is which? Can they spot the blasts?

Modelling activity:

Using the play dough model one of the cells we have learned about. Guess which one and recap what that cell does.

Extra activities:

Memory cards with blood cells on.

Pin the heart on the torso.

Heart jigsaw/ circulatory system.

Workshop Three

Aims:

* To understand that the body is made up of millions of different cells
* To understand that leukaemia results in changes to the white blood cells
* To understand that DNA carries all the instructions to make us
* To understand that leukaemia results from changes to the DNA

Exploratory activity

1. Recap the blood cells from last week and what goes wrong in leukaemia- low mature wbc, rbc, platelets. High numbers of blasts. Brief recap of symptoms.
2. Identify the picture of healthy and leukaemic blood films.
3. Look at microscopes with blood slides. Draw a picture of what they have seen. Can they identify the patient with leukaemia?
4. Models of cells- shows that cells have complicated insides. Not all cells are the same shape. Lots of different types that do different things. Match the picture of cell to what it is:

Nerve cell

Cone cell from the eye

Red blood cell

White blood cell

Liver cell

Cardiac cell

Skin cell

Brain cell/neuron

Cells are the building blocks of the body.

1. Cell quiz:

How many cells are there in the human body- 50-100 million million

How many different types of cells do we have? Over 200

How many new red blood cells does your body make every second? About 2.4 million.

How many new brain cells does your body make every day? None

What is the most common cell in the human body? Red blood cells

You can see cells with…… the naked eye, a microscope, a pair of binoculars?

1. Looking inside a cell

If you looked inside a cell you would see that the insides are complicated. Organelles which have different jobs. Look at cell models.

Activity One: Cell factory game

1. Look again at the model of the cell. See that it has little things inside it. These are called organelles and they have different jobs. The cell is like a factory where the organelles are different workers. Match the organelles to their functions using the factory pictures.
2. Making a model of a cell and matching the function of organelles to roles in a factory.

Cell membrane with gates to let things in and out.

Mitochondria- Powers the cell

Lysosomes- Gets rid of waste eg. Food, organelles, cells

Nucleus- Control centre. Takes in information and gives instructions.

Ribosomes- Uses instructions to make proteins.

Endoplasmic reticulum- works with ribosomes to make proteins

Golgi apparatus- Packages proteins ready for use outside the cell. Makes larger molecules. Makes lysosomes.

Cytoplasm- everything suspended in this. Gives the cell structure.

Vesicles – little bubbles. This is how things move around and out of the cell.

Activity Two: DNA chain activity

If you looked inside the nucleus you would find DNA which carries all the information to make our bodies. Written using four bases/letters. Like a book or a recipe.

1. Chain activity- sometimes the DNA can get mixed up and the sequence no longer makes any sense. In leukaemia normal blood cell growth and replacement goes out of control.

Using stringing beads with letters give them a word (could be their name) and let them mix it up and replace on the string. Does it still make sense?

What causes leukaemia?

Probably genetic and environmental causes. Radiation, chemical exposure. Poss links with exposure to normal infections in early childhood but can’t find specific causes and many findings are controversial. Also, different causes for different children. But not like other illnesses that you can catch.

Workshop Four

Exploratory activities

1. ‘Exploring the senses’ activities

Model of the eye

Model of the ear

Smell activity

Lucky dip box

What are the 5 senses. What body part is associated with each. Example of things we can sense.

1. How do the sense organs send messages to the brain? Recap nerve cells from the last session.

Activity One: Rope and Donut exercise

1. The rope represents the nerve and the rings represent a stimulus. One end of the rope is the sense organ which sends an impulse to the brain at the other end. Children at each end of the rope- one will be the brain and one a sense organ (let them choose which). The following are stimulus examples (show examples but they can choose their own): send messages to each other down the nerve

Stroking a dog

Having an injection

Medical procedures

Shutting your finger in a door

Falling over

Having a swim

Lying in bed

Having a cuddle from your mum

Picking up a hot plate

Holding a hand warmer

Send the message to the brain. Other child to choose the response (following are examples)

In choosing a response emphasise that one person’s response will be different from another’s. Why do we worry more about having an injection than falling over and hurting ourselves? Sometimes it is the anticipation that makes pain worse. If we think it will hurt it is more likely to. Thinking positive thoughts is likely to help reduce pain and feel good about themselves. How do the children cope with injections and other painful procedures?

Activity Two: ‘Healthy living exercise’

1. Why is it important to keep healthy?: relate to late effects of chemotherapy

Keeping active: able to do more things

Feel better: more energy, feel happier, able to concentrate better.

Look after future health: less likely to get sick in the future.

1. How can we keep healthy?

Diet

What does it mean to have a healthy balanced diet?

What are their favourite foods?

What fruit/veg do they like?

Do they eat breakfast?

Use the healthy food cards to split into good and bad. 10 cards each.

Exercise

How much exercise do they get?

What activities do they enjoy doing?

How much TV do they watch?

Sleep

What time do they go to sleep at night and what time do they get up?

What do you feel like if you’ve not had enough sleep?

Drinks

What are the best drinks to have and the worst?

How can you tell if you are not drinking enough?

Relaxation

What do they like to do to relax?

Time with friends/family

What do they enjoy doing with their friends/family?

Avoid bad things like smoking, too much alcohol

Avoid too much sun

Do they wear sunscreen if they go out in the sun/ on holiday?

Have they ever had sunburn?

Hygiene

Why is it important to wash and clean their teeth?

Going to health appointments

What health appointments do they go to?

Why is it important to go?

1. Health star activity:

Choose 5 foods and 5 activities from picture cards. See how many stars they earn (stars represent how healthy each is: on the back of the card).

1. Choose 3 things they think they could do to be healthier. Record their chosen changes.

Appendix B: Questions used to measure child confidence and treatment-related anxiety

Section E. How you feel about your child’s treatment.

We would like to ask you about how anxious you and your child have been in the past *4 WEEKS* compared with previous appointments. Please complete the following questions for your own feelings and then for your opinion of your child’s feelings.

*Your own feelings*

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  |  | Much less anxious than usual |  | The same as usual |  | Much more anxious than usual |
| 1. | Thinking about coming to clinic appointments, I have felt… | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2. | Thinking about my child’s Vincristine injections, I have felt… | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3. | Thinking about my child’s lumbar punctures, I have felt… | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

*Your child’s feelings*

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  |  | Much less anxious than usual |  | The same as usual |  | Much more anxious than usual |
| 1. | Thinking about coming to clinic appointments, my child has felt… | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2. | Thinking about Vincristine injections, my child has felt… | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3. | Thinking about lumbar punctures, my child has felt… | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

### Section F. Your child’s confidence

How does your child deal with health problems that sometimes occur? Please rate how confident your child feels when doing any of the following activities by circling the appropriate number.

*How confident is your child that he/she can…*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | **Not at all confident** |  | **Totally** **confident** |
| 1. | Ask your doctor about matters of concern? | 0 | 1 | 2 | 3 | 4 |
| 2. | Discuss openly with the doctor any school problems that may be related to the illness? | 0 | 1 | 2 | 3 | 4 |
| 3. | Do the different tasks and activities needed to keep healthy? | 0 | 1 | 2 | 3 | 4 |
| 4. | Reduce any emotional distress caused by the illness so that it does not affect everyday life? | 0 | 1 | 2 | 3 | 4 |
| 5. | Manage physical discomfort or pain? | 0 | 1 | 2 | 3 | 4 |
| 6. | Explain to others why time off school is needed for clinic visits? | 0 | 1 | 2 | 3 | 4 |
| 7. | Keep any health problems from interfering with the things he/she wants to do? | 0 | 1 | 2 | 3 | 4 |

**Appendix C: Parent and child qualitative questionnaires**

**Child questions:**

Thank you very much for taking part in the workshops. We really want to find out more about what you thought of them.

1. How did you find the workshops (please circle a response below):

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Were the workshops: | Yes very much  | Yes, a bit | No, not much | No, not at all |
| Fun | 0 | 1 | 2 | 3 |
| Interesting | 0 | 1 | 2 | 3 |
| Scary | 0 | 1 | 2 | 3 |
| Friendly | 0 | 1 | 2 | 3 |
| Easy | 0 | 1 | 2 | 3 |
| Boring | 0 | 1 | 2 | 3 |
| Difficult | 0 | 1 | 2 | 3 |

1. What did you most enjoy about the workshops?
2. Was there anything you didn’t enjoy?
3. Did you learn anything from the workshops (please circle)?: Yes/ No

If yes, please tell us about that here:

1. We want to know if you found the workshops easy or difficult to understand. For each topic, please circle a response:

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Topics we coveredIn the workshop | Easy to understand | Quite hard to understand | Very hard to understand | Not sure or can’t remember |
| The structure of the human body eg. Bones, organs, the heart etc. | 0 | 1 | 2 | 3 |
| The effects of chemotherapy on the body | 0 | 1 | 2 | 3 |
| Blood: what blood is made of and how it is different in leukaemia | 0 | 1 | 2 | 3 |
| Cells: different types and what is inside a cell | 0 | 1 | 2 | 3 |
| DNA and what happens if it goes wrong | 0 | 1 | 2 | 3 |
| The senses and how nerves send messages round the body | 0 | 1 | 2 | 3 |
| Keeping healthy: how to lead a healthy lifestyle and make healthy choices | 0 | 1 | 2 | 3 |

1. Have the workshops changed how you think about leukaemia (for example do you understand anything you didn’t before or do you find it easier to explain to people) (please circle)? Yes/ No

 If yes, can you tell us how?

1. Is there anything you would like to change about the workshops (please circle)? Yes/ No

If yes , what would you like to change?

1. How helpful do you think the workshops would be to other children with leukaemia (please circle one of the answers below)?

Not very helpful A bit helpful Very helpful

Could you tell us why?

**Parent questions:**

Thank you very much for bringing your child to the workshops. We appreciate the time you have taken out to do this and to complete all of the questionnaires we have sent to you.

We would really like to know what you thought of the workshops so that we can make improvements in the future.

Please feel free to write as much or as little as you like in the space provided below

Taking part in the workshops

1. How easy did you find it to attend the workshops? If you faced any difficulties could you let us know what they were?
2. Please tell us why you decided to take part in the study?

Evaluation of the workshops

1. Do you think your child gained anything from the workshops? If so what and could you please explain why?
2. What would your child say were the best or worst parts of the workshops? Please tell us if there were specific things your child mentioned about the workshops (for example if there were things they really enjoyed or things they didn’t like).
3. How do you think the workshops have changed how your child thinks or talks about leukaemia, if at all?
4. Are there any other things you think we should have covered in the workshops?

YES / NO (please circle) If yes, Please tell us what .....

1. Would you recommend the workshops to other families?

YES / NO (please circle). Could you tell us why?

1. Do you have any other comments which could help us to improve the workshops in the future?

**Appendix D: Individual plots for parent-reported PedsQl (generic) total score and child-reported PedsQl (cancer) total score**





**Appendix E: Interview schedule for parent interviews**

Semi structured schedule for interview study

# Introduction

Thank you for agreeing to take part in our study. We are evaluating our workshops to find out where we need to make improvements. We want to speak to parents who decided not to take part. This way we can decide where to make changes to inform future workshops. Please feel free to say whatever you want. We are interested in all feedback from parents both positive and negative.

As well as asking about what you thought of the workshops we will also ask you some questions about your child and how they were affected by being treated for leukaemia. This is because leukaemia affects children and families in different ways and we want to understand this better so we can make the workshops useful for as many children as we can.

**Information about the family**

Can we start by finding about a bit more about you and your child and how things have been for you?

1. Can you tell me a bit about (child’s name)?
2. How did (child’s name) diagnosis and treatment affect your family?
3. Can you tell me a bit about how things have been since you received (child’s name) diagnosis?
4. How would you say things were at the time we approached you about this intervention?

# Information about non-participation

1. Could you tell me why you and/or (child’s name) decided not to participate in the workshops?

(Prompt: once they have talked about a reason ask them if there was anything else.)

1. Is there anything we could have done to make the workshops more accessible or more appealing to you or (child’s name)?
2. Could you see any advantages to (child’s name) attending the workshops?
3. Do you think the intervention could be useful for other families? Why?

# Information about communication about leukaemia

1. a) Did (child’s name) understand what was happening to them when they had leukaemia?

b) Do you think you understood leukaemia when (child’s name) was diagnosed?

1. As a family how did you approach finding out about/getting information about leukaemia? (Prompts: Did (child’s name) show an interest in wanting to know/learn about leukaemia or did they prefer not to know about it? How about you? Can you say something about why you think this was?
2. As a family how have you approached talking about leukaemia?