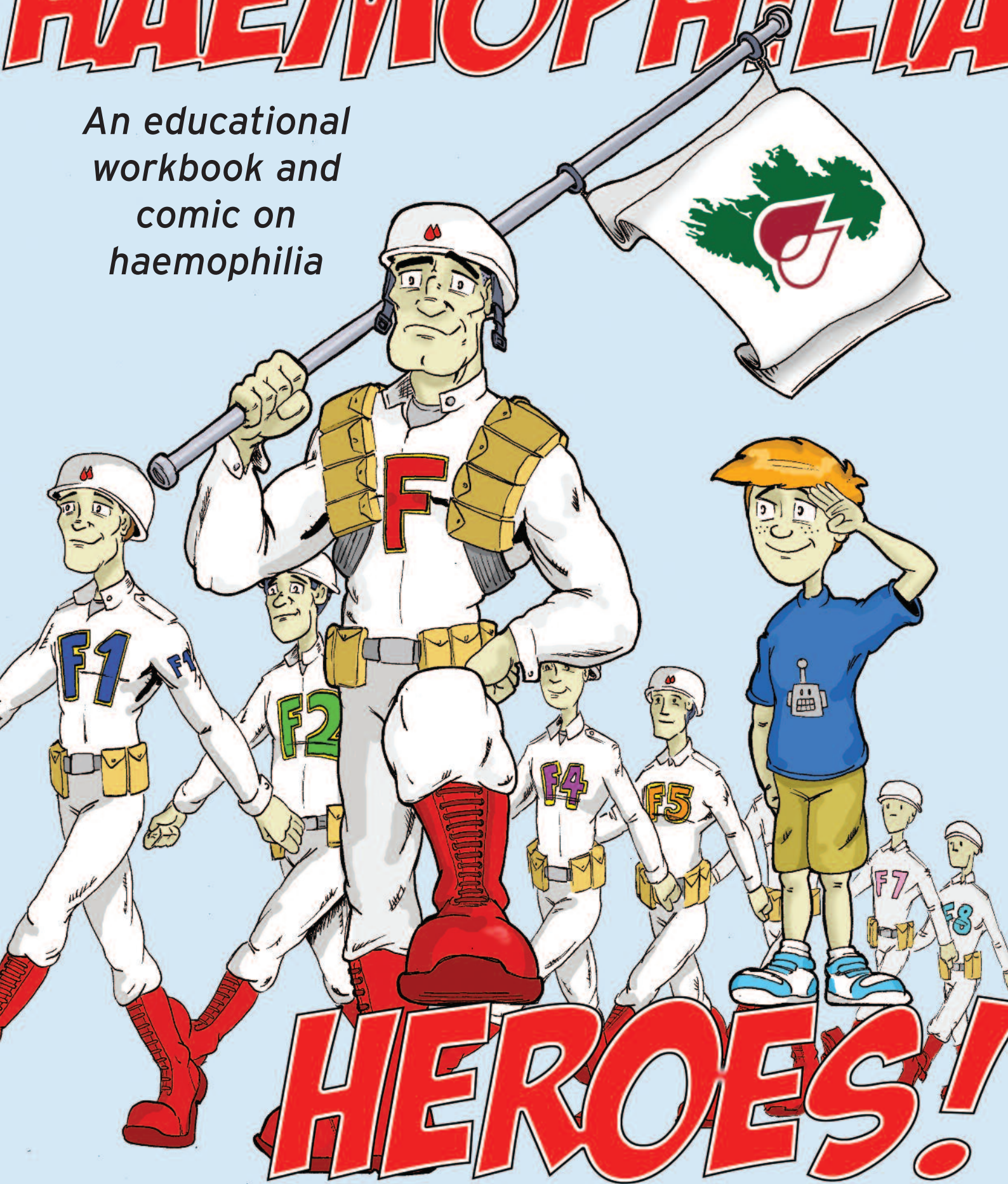


HAEMOPHILIA

An educational
workbook and
comic on
haemophilia



Introducing...

CAPTAIN FACTOR



ATTENTION!

Hello and welcome to Haemophilia Heroes - a workbook for children with haemophilia.

I will be your captain and I am here to help you understand haemophilia, but before we learn about haemophilia I need to know a little bit about you!

ME

My name is _____.

I am _____ years old.

I have _____ sisters and _____ brothers.

I have a bleeding disorder called _____.

This book is about me and my haemophilia and tells the story of how I am unique.

Nice to meet you recruit.

Now its time to learn, so get your pens and markers at the ready and lets begin!

Wherever you see this blue colour there is an activity that you need to do! Don't forget to colour in the characters as you go!



What is haemophilia?

Haemophilia (He - moe - fill - e - a) is a bleeding disorder. It means your blood works differently to most people because you are missing a factor.

What is a factor?

Blood is made up of 13 factors which work together to form a clot. A clot is a plug which forms when we cut ourselves and stops the blood from leaving our body, because you are missing a factor this means it takes longer for a clot to form so you bleed for longer.

How do you prevent bleeding?

I take treatment _____ times a week, this is called prophylaxis (Pro - fill - axe - is). This treatment adds more factor to my blood so if I do hurt myself a clot can form. I still sometimes bleed for longer, but it means most of the time I am ok.

Are there different types of haemophilia?

Yes, there are two types of haemophilia known as A or B. Haemophilia A is when a person is missing Factor VIII (8) and Haemophilia B is when a person is missing Factor IX (9).

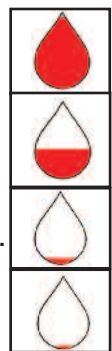
There are also different levels of haemophilia: mild, moderate (mod-or-it) and severe (siv-ear).

A person who does not have haemophilia has between 50% - 100% of factor in their blood.

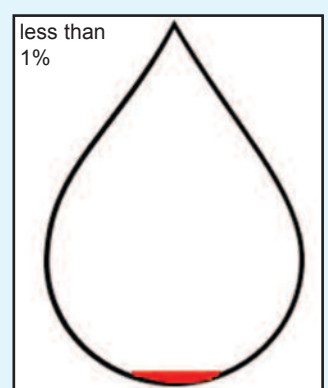
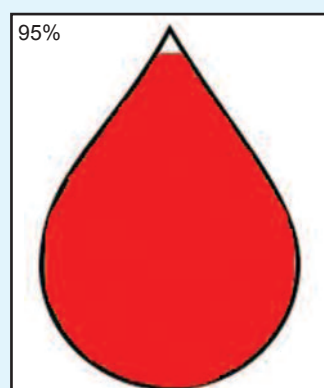
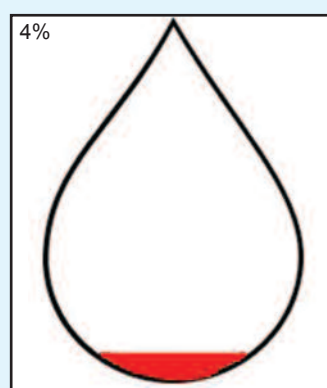
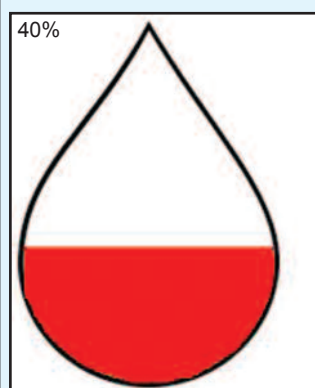
A person with mild haemophilia has between 5% to 40% of factor in their blood.

A person with moderate haemophilia has between 1% - 5% of factor in their blood.

A person with severe haemophilia has less than 1% of factor in their blood.



Can you identify the different levels of haemophilia in each picture below?

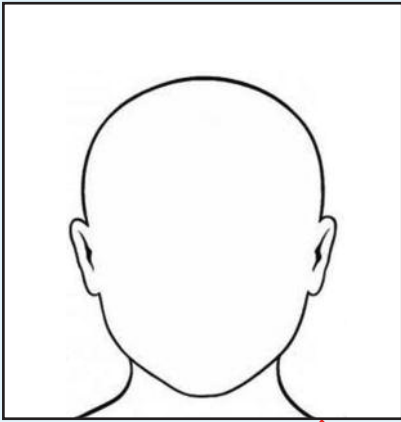


What type and level of haemophilia do you have? Cross out the words that do not apply to you.

I have mild / moderate / severe haemophilia A / B.

Meet me and my Family

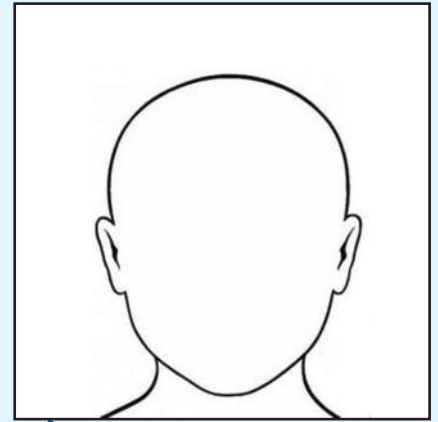
My Mam



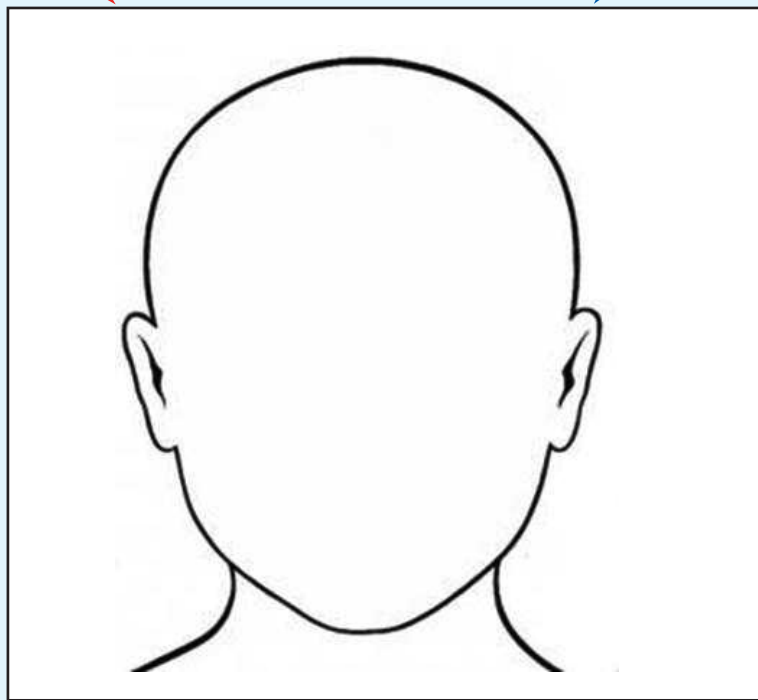
Time to draw!
On the faces below, draw you and your family.

What have you got in common with each member of your family - have you the same colour hair as your Mam or the same colour eyes as your Dad?

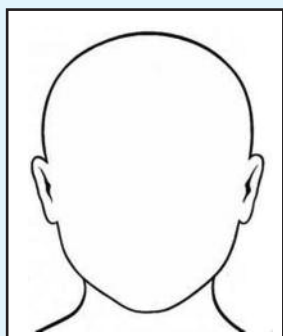
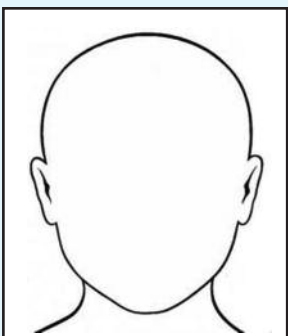
My Dad



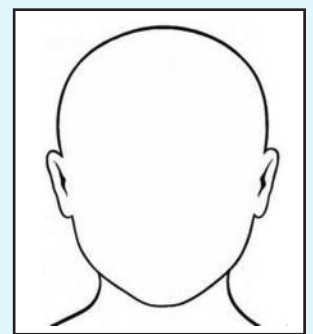
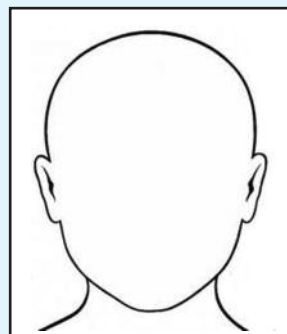
ME



My Brothers



My Sisters



Inheritance

Haemophilia is something you are born with and which you will have for your whole life.

When a boy is born with haemophilia there can be another member of your family who has haemophilia too, like your uncle or your grandfather. This type of haemophilia is called inherited (in – hair – it – did). The reason it is known as inherited haemophilia is because it is in your family before you were born. Everyone inherits things from their family like hair colour or eye colour.

My hair colour is _____ just like my _____.

My eye colour is _____ just like my _____.

Sometimes, you are the very first person with haemophilia in your family. This is called spontaneous haemophilia (sp-on-they-knee-us). It's a bit like magic, and like magic nobody knows why it happens.

How did you get your haemophilia?

Inherited _____

Spontaneous _____

Why do my brothers and sisters not have haemophilia?

Usually only boys have haemophilia, but sometimes not very often, girls can also get haemophilia. These are extra special girls. If you have a sister she may not have haemophilia, but when she gets older she might have a son who has haemophilia.

Even though haemophilia mainly happens in boys it doesn't mean you and your brother(s) will both have haemophilia.

FAMILY ACTIVITY

- 1) Get the family together.
- 2) Get a piece of paper and some different colour pens.
- 3) Starting with you and your brothers & sisters, work back through your parents and grandparents and create your very own family tree!
- 4) Mark anybody who has haemophilia with a red marker and anyone who doesn't have haemophilia with a blue.

Experiment

Flip a coin and count how many times you get heads and how many times you get tails. There is a 50/50 chance a person can inherit haemophilia when there is a family history just like there is a 50/50 chance of getting tails when you flip a coin!

Types of Bleeds

Bleeding can happen inside and outside the body.

When you cut yourself and you can see the blood, this is called external (x-turn-all) bleeding.

The second type of bleed is called internal (in-turn-all) bleeding. This is when you bleed on the inside of the body. If you fall, get a bang or get hit, you may damage yourself inside the body and although you cannot see any blood you may have bleeding inside and might need to take your factor straight away. When you bleed into your muscles (forearm, calf) or joints (knees, ankles, elbows) these are internal bleeds. When a person with haemophilia has lots of bleeds in the one area this is called a **target joint**.

So, am I ok as long as I don't get a cut?

You are ok, but you have to be careful because sometimes when you fall you might not get a cut, but you could still be in pain. If this happens it could be a sign that you are bleeding on the inside and you should tell an adult as soon as possible.

Which is worse an internal bleed or an external bleed?

Both internal and external bleeds are bad and if you hurt yourself you should always tell your parents or your teachers so they can help you and make sure you are ok. Internal bleeding is worse because if people cannot see blood they might not know you are hurt. Sometimes it is hard to know when you have an internal bleed, but if you think you do, you should tell someone straight away because you may need to take factor and the longer you go without factor the more painful it will become.

My name is Max. My knee is very sore because I have a bleed. I always get bleeds in my knee, the doctor says this is because my knee is my target joint.

External

Internal

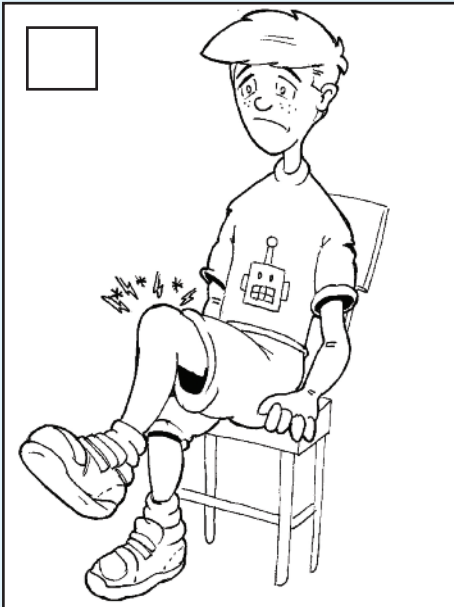
On the body above circle all the places you have had a bleed in **red**.
In **blue**, circle your target joints.
Then count how many are external and how many are internal.

Signs of a Bleed

It is easy to know when I have cut myself because there is blood, but how will I know when I am bleeding inside?

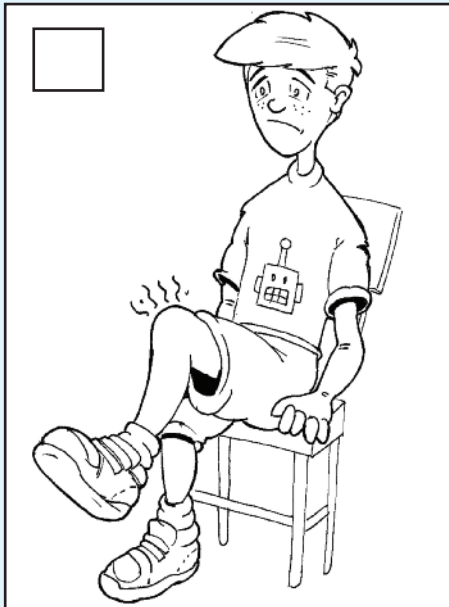
Everybody is different, but most people with haemophilia say there are “feelings” they get when they have a bleed which tells them that they need to take factor.

Below are pictures of some different feelings that many people with haemophilia have when they have a bleed. Colour in the pictures if you experience the feeling when you have a bleed.



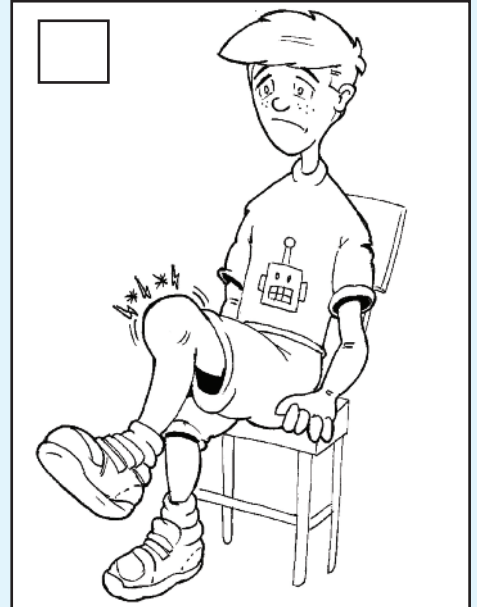
Pain

Having a bleed can be very sore and your leg might start to hurt a lot.



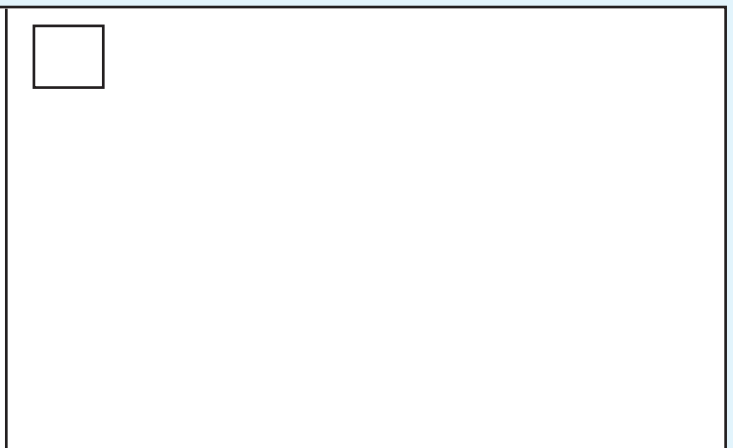
Heat

When a bleed happens your leg might suddenly start to feel warmer than the rest of your body.



Swelling

Your knee might start to swell and feel very tight.



What do you feel?

In the boxes above write and draw some of the feelings you have when you have a bleed! When you have all the feelings coloured in, number them in the order they happen.

Treating a Bleed

What should I do when I have a bleed?

If you think you have a bleed you should always tell an adult so they can help you take your factor and make sure you are ok. Even if you are not sure you have a bleed it is better to be safe and take factor because if you do not take factor and you do have a bleed, it will be more painful!

There are two ways to get your factor - into your vein or through your port-a-cath (Freddie). A port-a-cath (Freddie) is a device under the skin that lets you take your factor while your veins are still growing.

It is important to rest after taking your factor so that the factor soldiers have time to get to work.

Below is a maze of what you should do when you have a bleed. Can you make your way through the maze? Make sure you go through each stage!!

FINISH
Rest



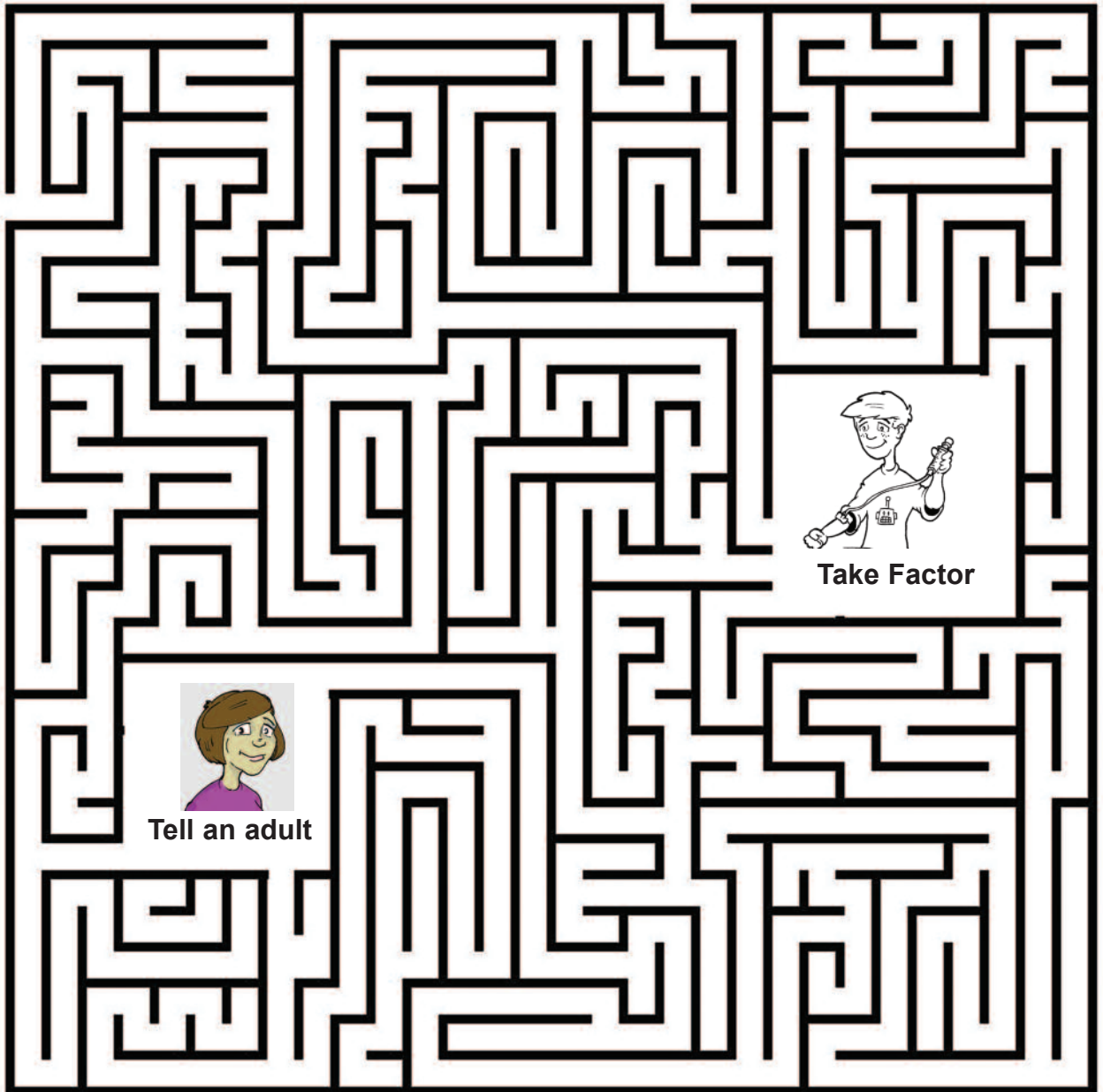
START
A Bleed
Occurs



Take Factor



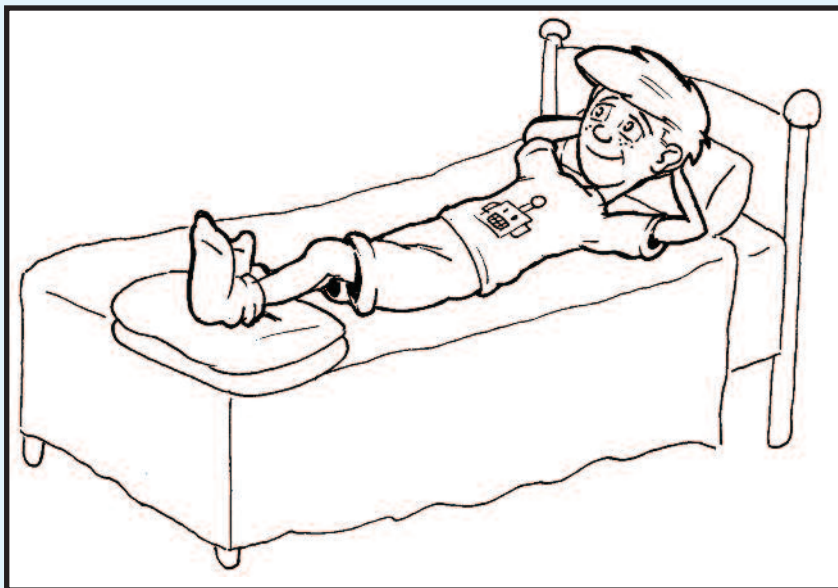
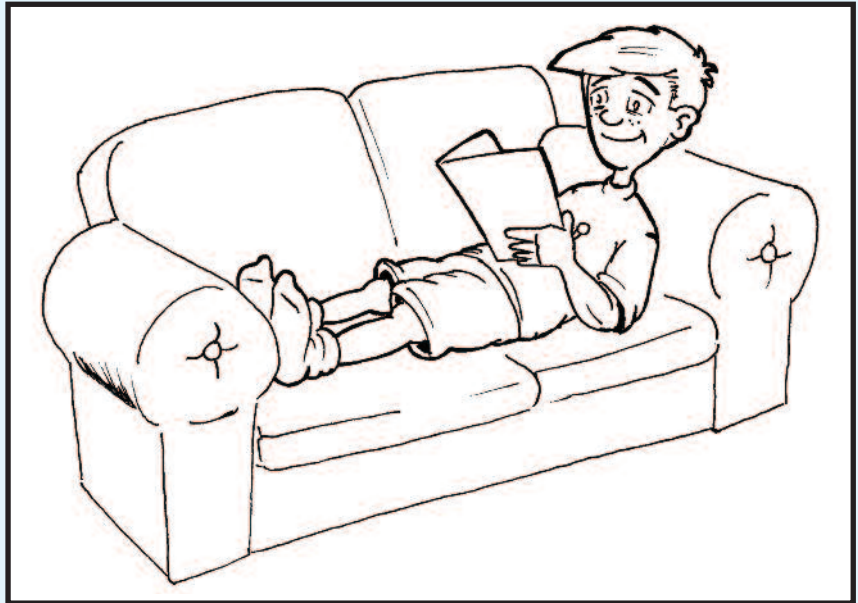
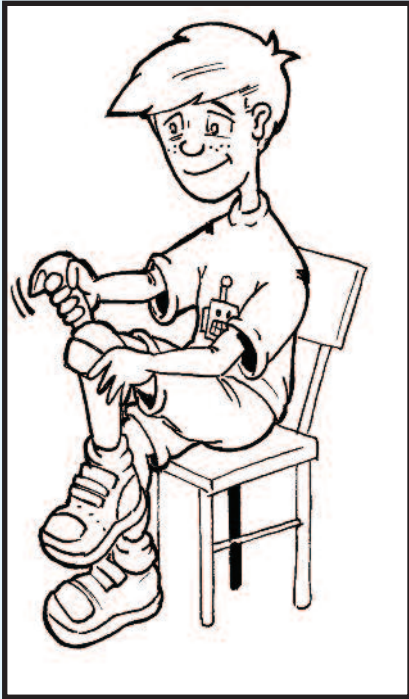
Tell an adult



R.I.C.E.

When you have haemophilia it is very important to look after yourself. There are four simple steps to keeping healthy and safe - **R.I.C.E.** - Rest, Ice, Compression and Elevation.

Write the word underneath the picture matching its action.



Self Infusion

What should I do when I have a bleed?

Number the steps of self infusion in order.



CLEAN HANDS



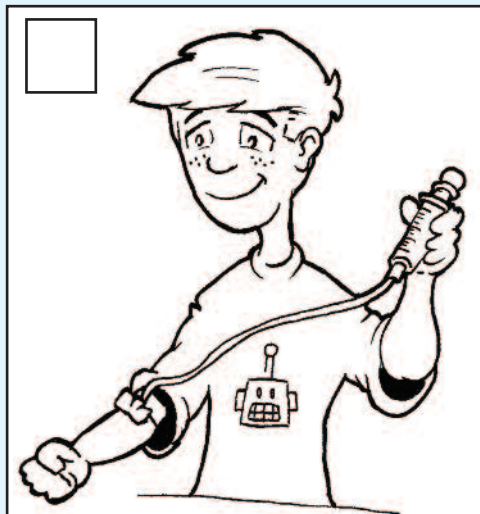
CLEAN INFUSION SITE



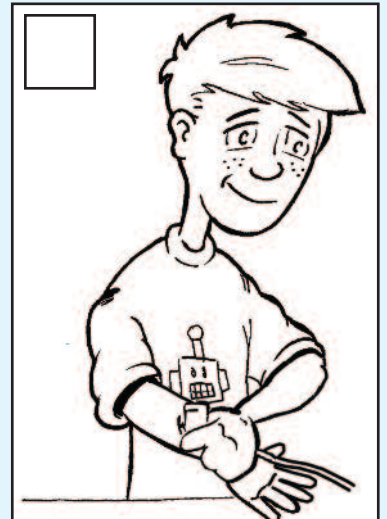
CLEAN FACTOR



DRAW FACTOR INTO SYRINGE



INFUSE FACTOR



ACCESS VEIN



SECURE TOURNIQUET



MIX FACTOR

Family Activity

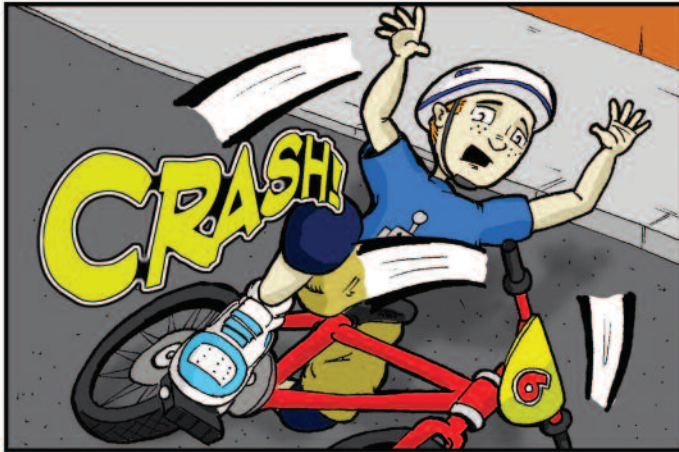
Don't worry if you are not able to self infuse, it is like learning to ride a bike, it takes time. If you are not ready to learn, why not ask your Mam and Dad to let you help set up the treatment for your infusion.

Answers: 1) Clean Hands, 2) Clean Factor, 3) Mix Factor, 4) Draw Factor into Syringe, 5) Secure Tourniquet, 6) Clean Infusion Site, 7) Access Vein, 8) Infuse Factor.

HAEMOPHILIA HEROES!



THIS IS MAX. HE IS SIX YEARS OLD AND HE HAS SEVERE HAEMOPHILIA, BUT UNTIL RECENTLY HE DID NOT UNDERSTAND WHAT THIS MEANT.



ARE YOU OKAY, MAX?

MY KNEE FEELS FUNNY, I THINK I HAVE A BLEED. CAN YOU GET MY MAM AND DAD?



MAX'S PARENTS ARRIVE...

WHAT'S HAPPENED HERE, THEN?

I FELL OFF MY BIKE AND BANGED MY KNEE. I THINK I HAVE A BLEED.

WE HAD BETTER GET YOU HOME AND GIVE YOU SOME FACTOR!



FEEL BETTER!

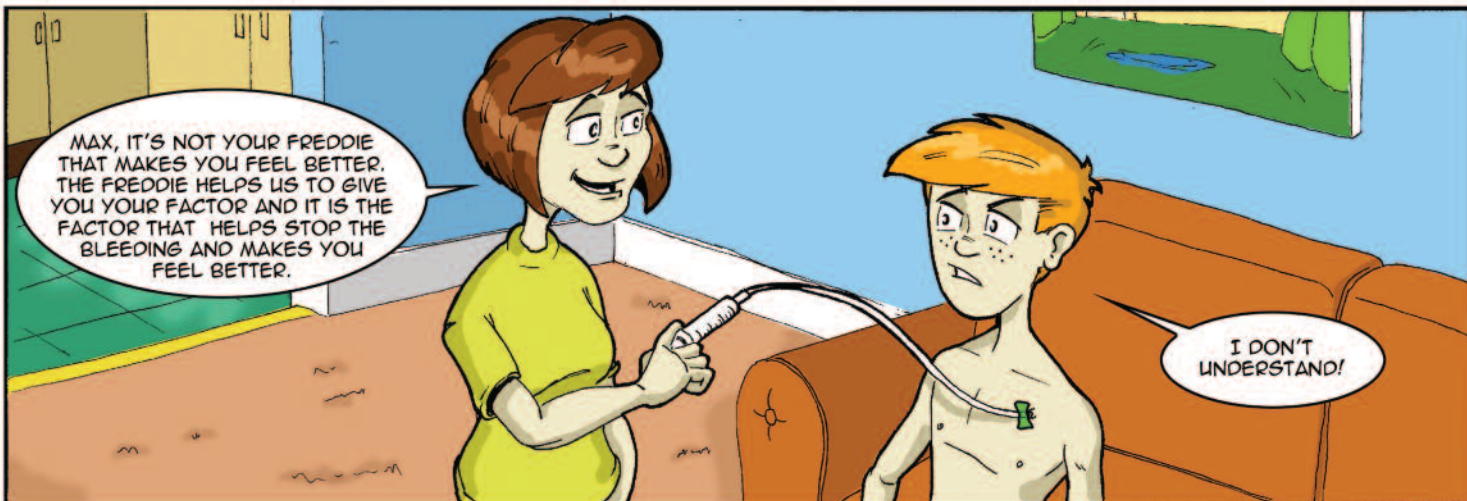
HOPE YOU ARE OKAY!

DON'T WORRY, I'LL BE BACK IN A LITTLE WHILE. I JUST HAVE TO TAKE MY MEDICINE. MY FREDDIE WILL MAKE ME FEEL BETTER!



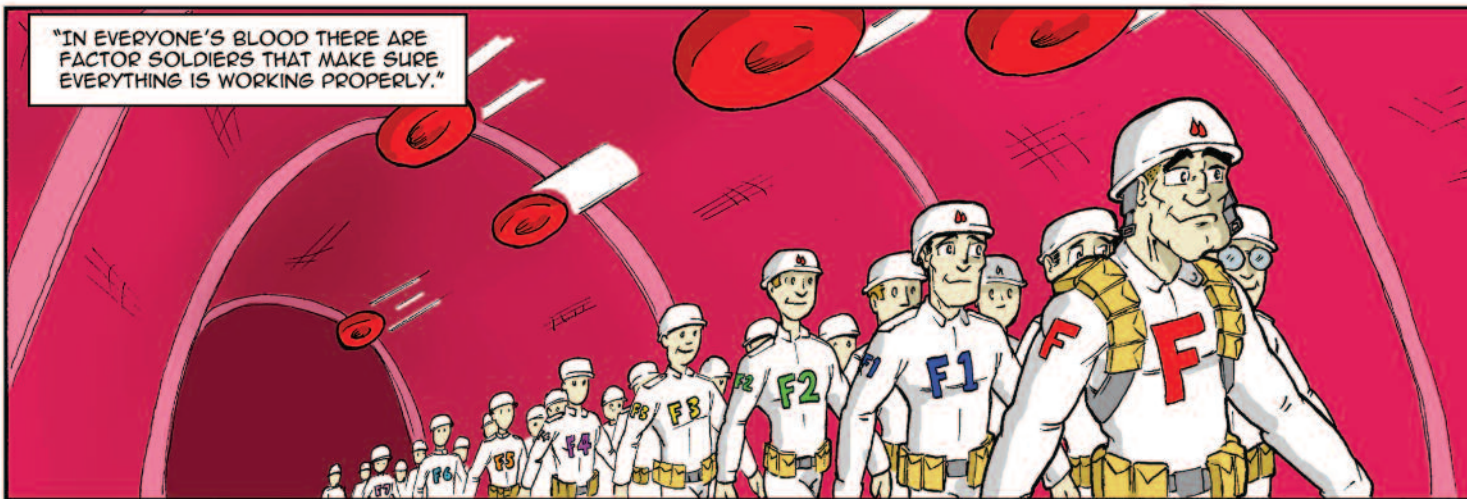
MAX, WHAT DID YOU MEAN WHEN YOU TOLD YOUR FRIENDS YOUR FREDDIE WOULD MAKE YOU FEEL BETTER?

MY FREDDIE STOPS MY BLEEDS AND MAKES ME FEEL BETTER!

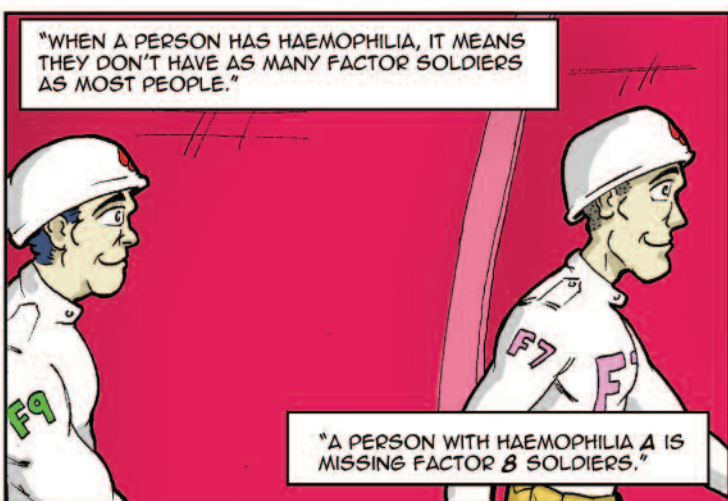


MAX, IT'S NOT YOUR FREDDIE THAT MAKES YOU FEEL BETTER. THE FREDDIE HELPS US TO GIVE YOU YOUR FACTOR AND IT IS THE FACTOR THAT HELPS STOP THE BLEEDING AND MAKES YOU FEEL BETTER.

I DON'T UNDERSTAND!

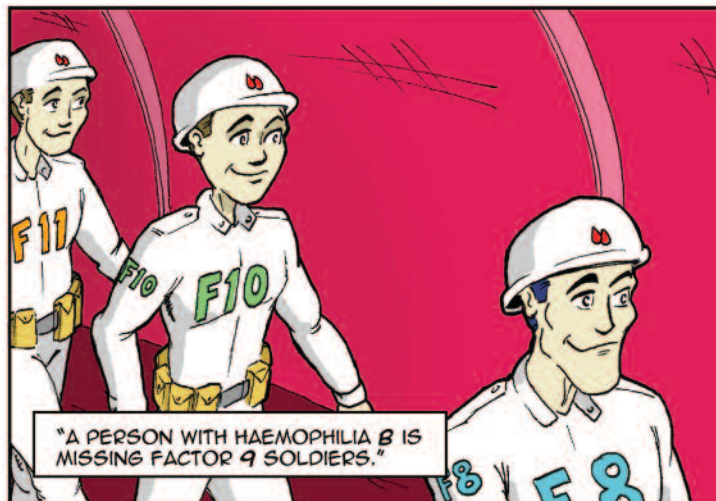


"IN EVERYONE'S BLOOD THERE ARE FACTOR SOLDIERS THAT MAKE SURE EVERYTHING IS WORKING PROPERLY."



"WHEN A PERSON HAS HAEMOPHILIA, IT MEANS THEY DON'T HAVE AS MANY FACTOR SOLDIERS AS MOST PEOPLE."

"A PERSON WITH HAEMOPHILIA A IS MISSING FACTOR B SOLDIERS."

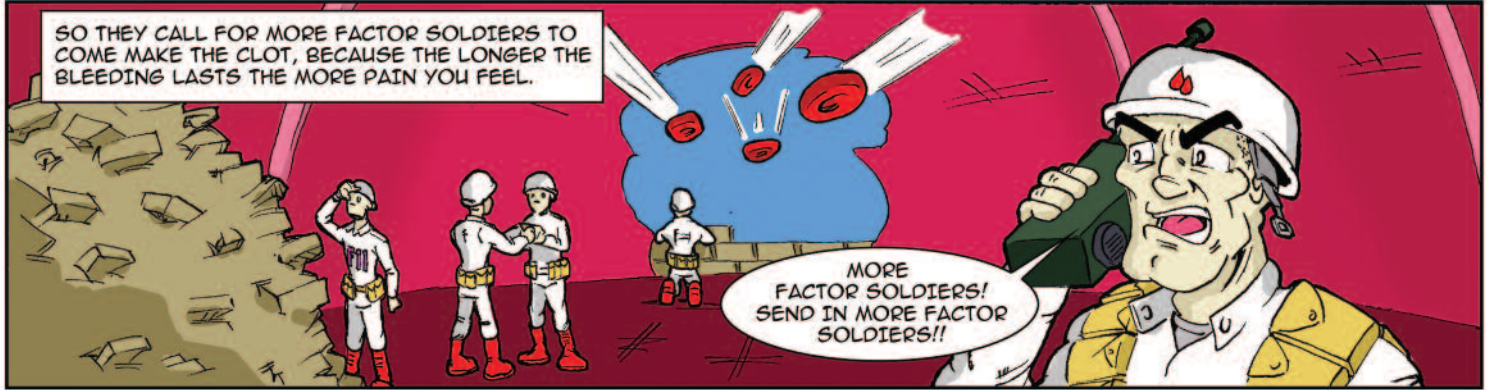


"A PERSON WITH HAEMOPHILIA B IS MISSING FACTOR 9 SOLDIERS."

THIS MEANS THAT WHEN A PERSON WITH HAEMOPHILIA HAS A BLEED, THERE AREN'T ENOUGH SOLDIERS TO HELP BUILD THE CLOT THAT WILL STOP THE BLEEDING AND THIS IS WHEN YOU FEEL PAIN.



SO THEY CALL FOR MORE FACTOR SOLDIERS TO COME MAKE THE CLOT, BECAUSE THE LONGER THE BLEEDING LASTS THE MORE PAIN YOU FEEL.

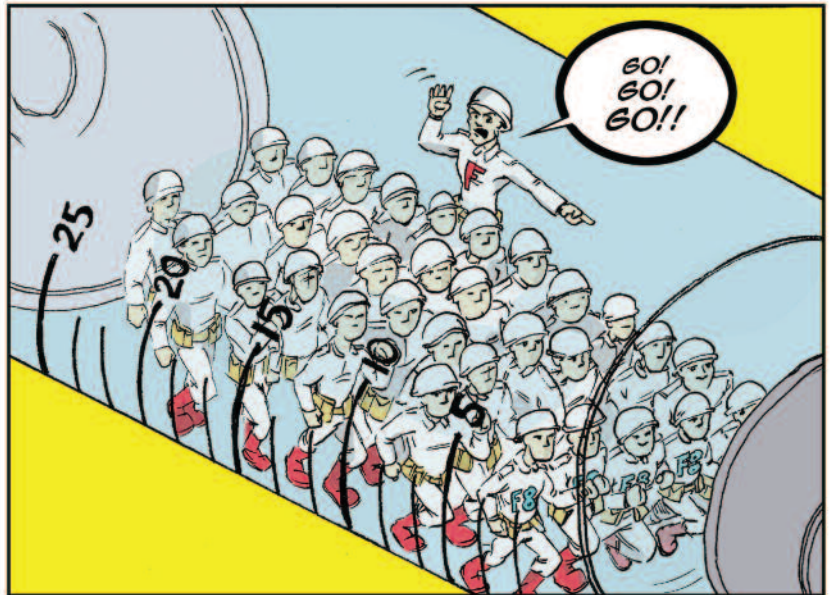


MORE FACTOR SOLDIERS!
SEND IN MORE FACTOR SOLDIERS!!

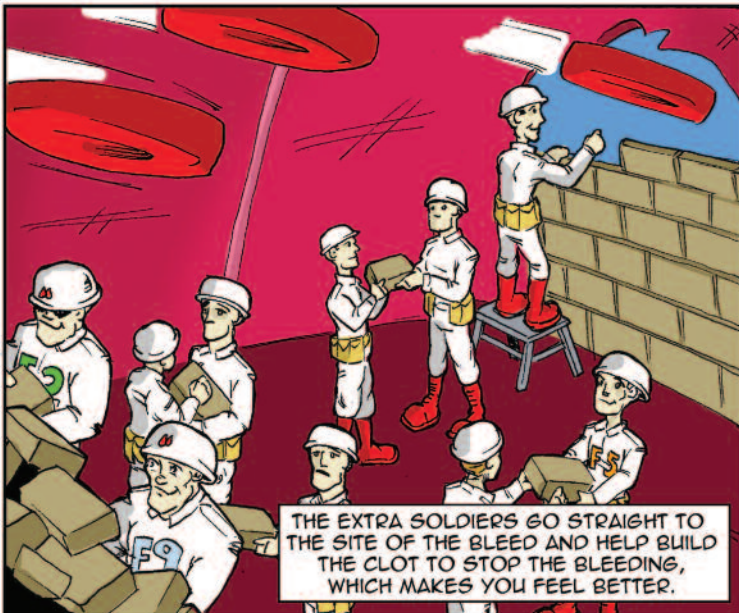
THIS IS WHEN WE GIVE YOU YOUR FACTOR AND SEND IN EXTRA SOLDIERS.



GO!
GO!
GO!!

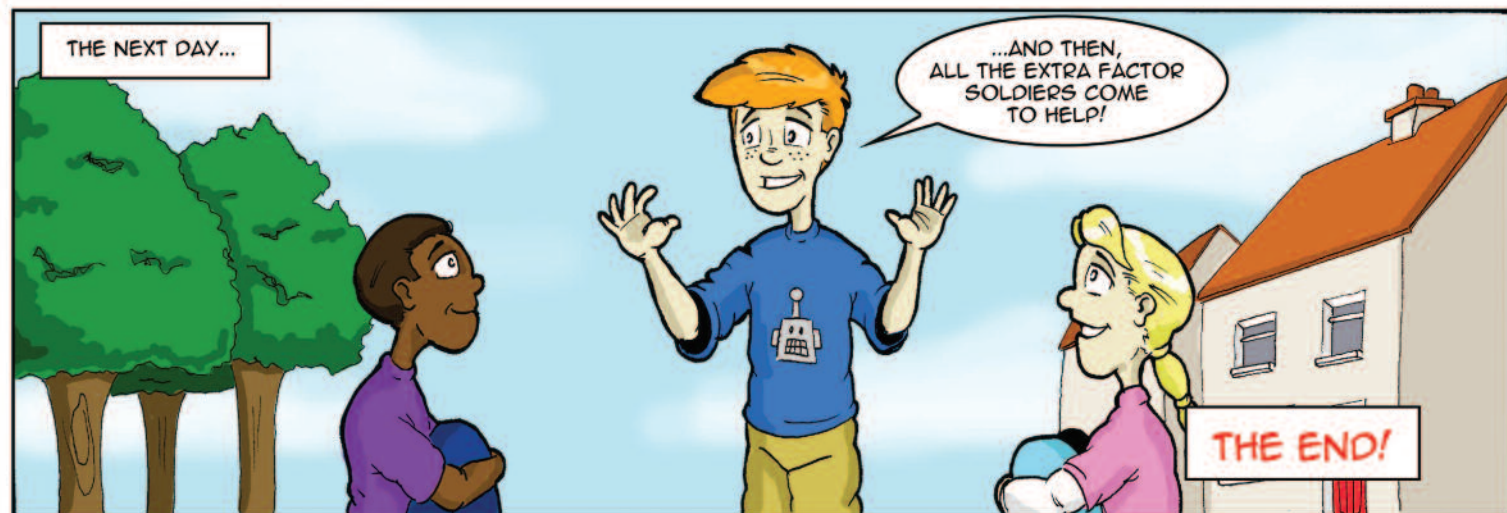
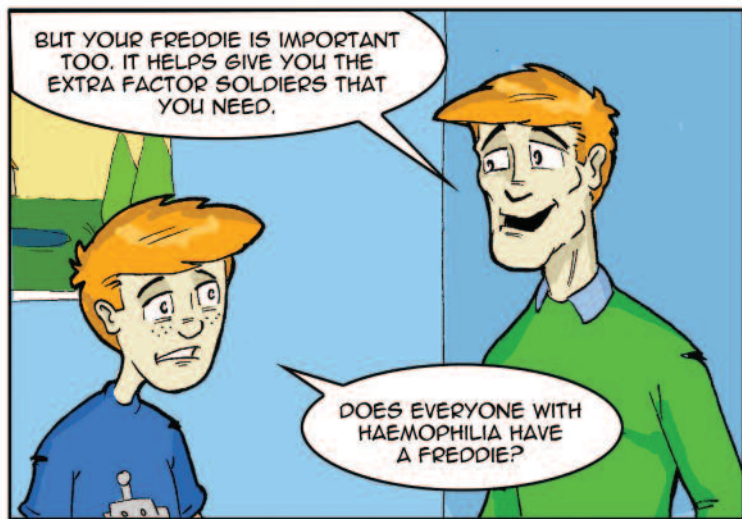


THE EXTRA SOLDIERS GO STRAIGHT TO THE SITE OF THE BLEED AND HELP BUILD THE CLOT TO STOP THE BLEEDING, WHICH MAKES YOU FEEL BETTER.



YAY!!



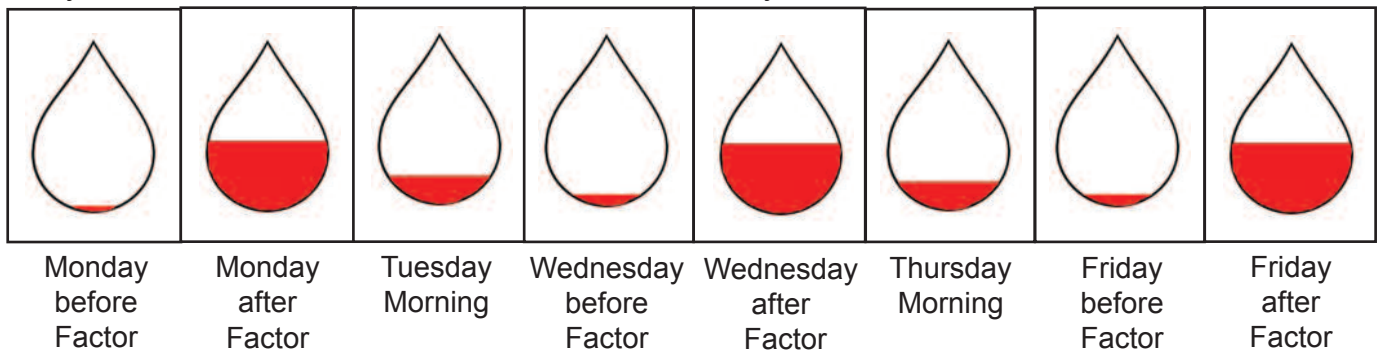


Prophylaxis

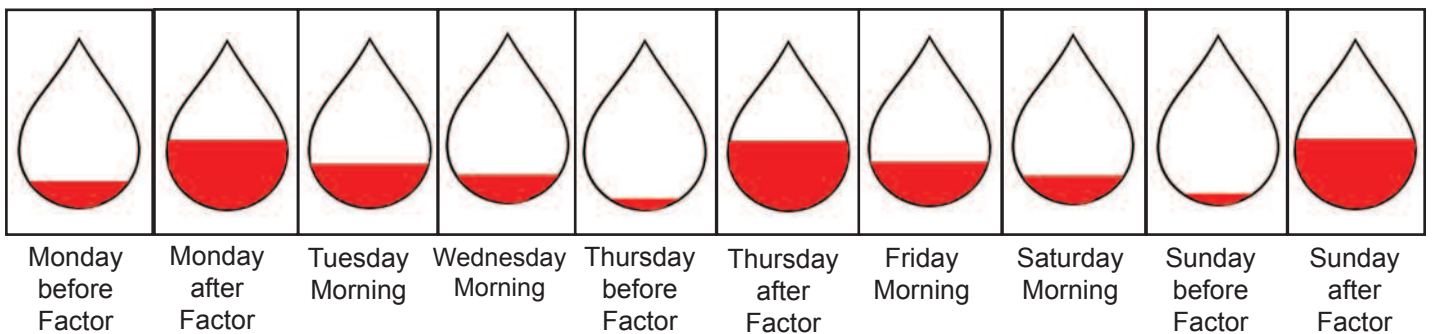
Why do I have to take my factor so many times a week?

When the factor soldiers are injected, they go to where they are needed (the site of the bleed). When they finish building the clot, the factor soldiers have used all their energy so they can't help anymore. Soldiers need to guard the clot to make sure it doesn't break, that's why you need to take more factor to make sure you have factor soldiers guarding the clots and ready to jump into action when you have a bleed. You should always have at least 1 set of soldiers (1% factor) in your blood and this is why you need to take factor regularly.

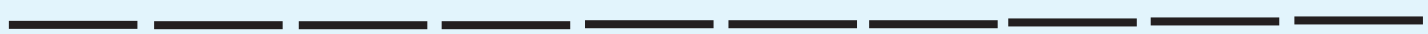
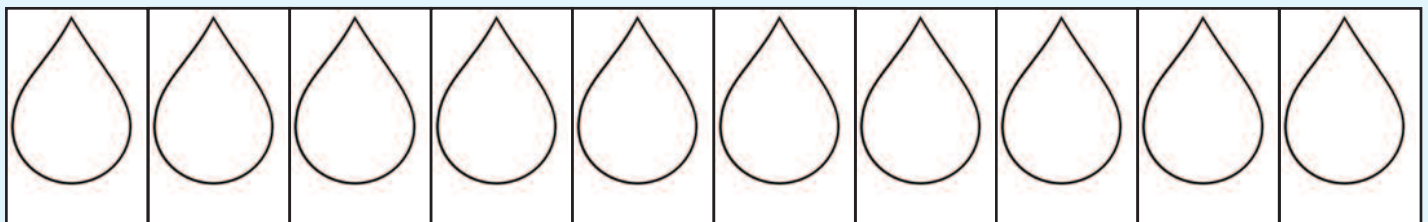
Max takes his factor every second day because he is missing Factor VIII (8) soldiers. The pictures below show how many factor soldiers there are in Max's blood. When the blood drop is mostly white it means there are not enough soldiers. When Max takes his factor the blood drop becomes mostly red to show that there are more soldiers on duty.



Factor IX (9) soldiers work the same way, but they can work for longer before all their energy is used up. Look at the pictures below - the blood drop is never completely white because the factor soldiers work until the new soldiers take over.



Keep a record of when you take your factor below. Try and figure out when you have to take your factor again without your mam or dad telling you - remember there should always be some factor soldiers in your blood!



Sport

Can I play sport even though I have haemophilia?

Yes! Sport is a form of exercise and exercise helps to keep you strong and healthy which is very important for people with haemophilia. When you have haemophilia, you need to have strong muscles because they help to protect your joints from bleeds.

You can try most sports, but if a sport or game makes you have bleeds then it might be better to stop playing that one. Swimming is a sport that is really good for you because it is good exercise, and the water acts like a cushion for your body. It is also a lot of fun!

JUST REMEMBER TO FOLLOW THE CAPTAIN'S CODE:



1. Factor Up

For some sports and games you may need to take factor. Make sure to do this as you may injure yourself!

2. Warm Up

You should always do some light stretches before playing sport as it helps to loosen your muscles and keep you injury free!

3. Dress Up

Always wear the right clothing for the sport you play e.g. wear your helmet when cycling and wear shin guards when playing soccer!

4. Warm Down

When you have finished playing do some light stretching again, this will help your muscles to relax and stop your muscles from cramping!

5. Write Down

Keep a record of the sports you play and when you have bleeds. If you are getting a lot of bleeds after playing a particular sport it may not be a good sport for you to play. Talk to your Mam and Dad about this.

It doesn't matter if you are not great at sports, the important thing is that you try to stay active and healthy. Everyone should do 30 minutes of exercise a day, so play a game of Wii-fit or go for a cycle – that's an order recruit!!

Below are a list of 30 different sports, some are very good for people with haemophilia, but some of the others may cause problems.

Write the names of the sports in the different boxes, Green is Great, Yellow is Good and Red is Bad.

Swimming	Soccer	Rugby	Karate	Hurling
GAA	Tai Chi	Tennis	Golf	Trampolining
Badminton	Boxing	Basketball	Cycling	Gymnastics
Running	Cricket	Fishing	Hockey	Ice Skating
Horse Riding	Judo	Handball	Rowing	Skiing
Squash	Archery	Wrestling	Surfing	Rollerblading

Go and Try it

Be Careful

Avoid

Answers:
Green sports: Swimming, Golf, Badminton, Cycling, Fishing.
Yellow sports: Soccer, Tai Chi, Tennis, Karate, Basketball, Running, Gymnastics, Cricket, Ice Skating, Horse Riding, Handball, Skiing, Squash, Surfing, Rollerblading, Rowing, Archery.
Red sports: Rugby, Trampolining, Hurling, GAA, Boxing, Hockey, Judo, Wrestling.

Feelings

Everyone has feelings and sometimes we can't help how we feel. It is important that we don't keep our feelings to ourselves. Sometimes you might be angry at your haemophilia or that you have to stay in hospital, but it is important to tell someone when you are feeling angry or sad. It is also important to remember things that make you happy.

Under the two headings below, write down things that make you happy and angry. If you have more than ten things on your angry list talk to your mam or dad.



ANGRY

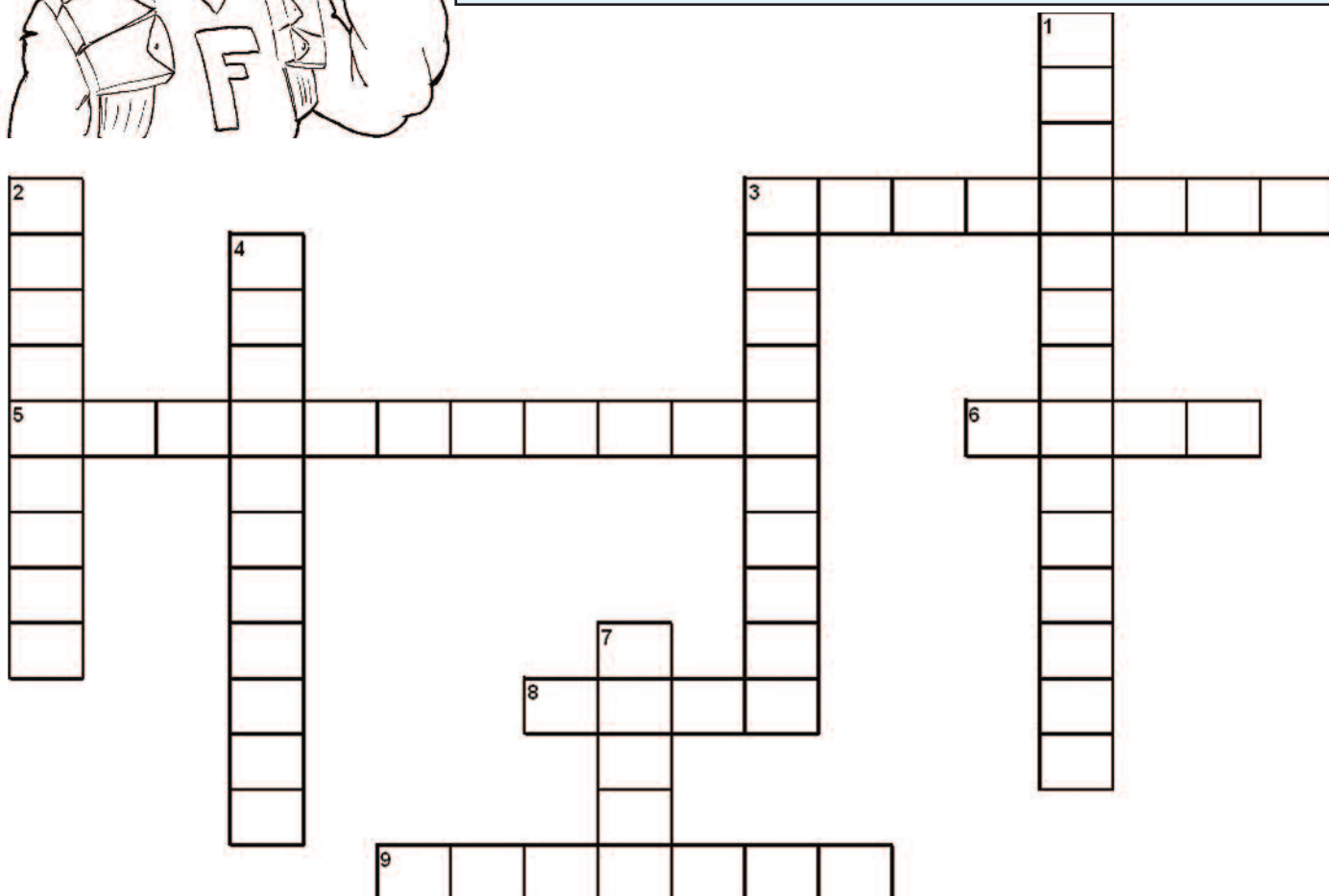
HAPPY

How much have you learnt?



Ok recruit its time to put your skills to the test. Using what you have learnt in the workbook can you solve the puzzles I have set out for you? Start with the crossword below, if you get stuck you can ask an adult for help or go back and read the book again.

When you are finished check if you got the answers right on page 23. Now get to work recruit!



Down:

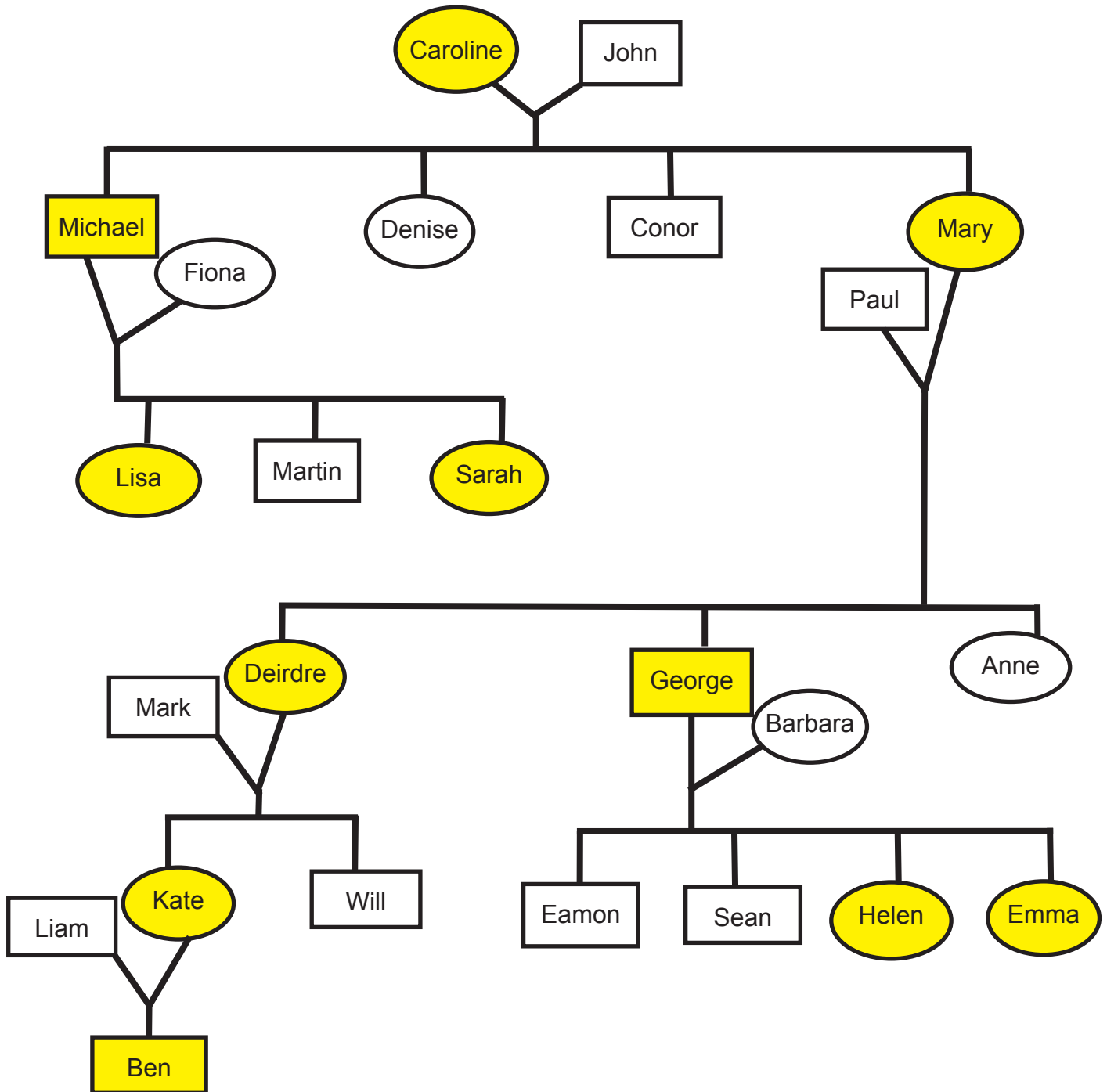
1. When you take your factor you are sending in more (6, 8)
2. You have this to get your factor (9)
3. You fasten this on your arm to take your factor (10)
4. The regular treatment for haemophilia is called (11)
7. People with haemophilia take factor to help prevent and treat a.... (5)

Across:

3. The first step in _____ a bleed is to tell an adult (8)
5. Rest, Ice, _____, Elevation (9)
6. When playing sport it is important to take care and follow the Captain's _____ (4)
8. Factor helps the blood to _____ which helps prevent and treat bleeds. (4)
9. A port-a-cath is also called a.... (7)

This chart shows how haemophilia is in Caroline's family. It shows Caroline's children, grand children, great grand children and great great grand children.

Look through the chart and see if you can answer the questions?



KEY



Man



Woman



Man with haemophilia



Carrier

Using the family chart on page 20, can you answer the questions below?

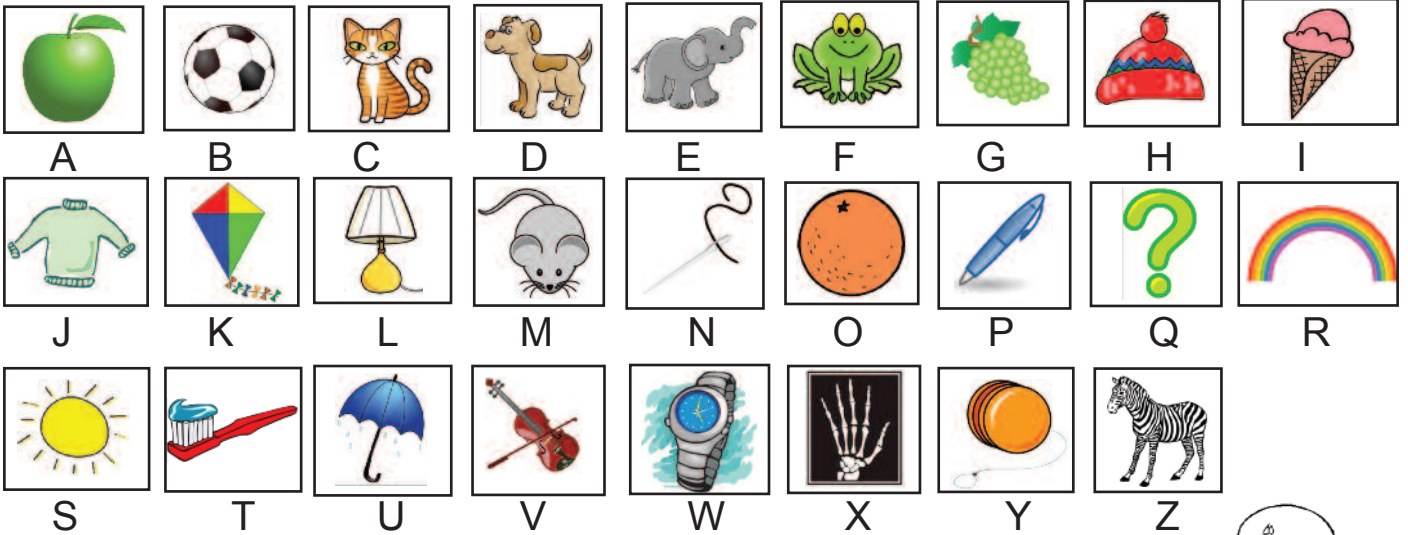
1. Caroline and John have four children, two daughters and two sons.
(A) One of their daughters is a carrier, what is her name? _____
- (B) One of their sons has haemophilia, what is his name? _____
- 2.. In total how many boys in the family have haemophilia? _____
3. In total how many girls in the family are carriers? _____
4. What relation is Ben to Caroline? _____
5. If Ben has a son, will he have haemophilia? _____
6. If Ben has a daughter, will she be a carrier? _____
7. If Helen has a son he will have haemophilia. TRUE or FALSE
8. If Emma has a daughter she will be a carrier. TRUE or FALSE

Remember though if you are the first person in your family with haemophilia your family might look like this some day maybe your great great great grandchildren will be looking back for you.

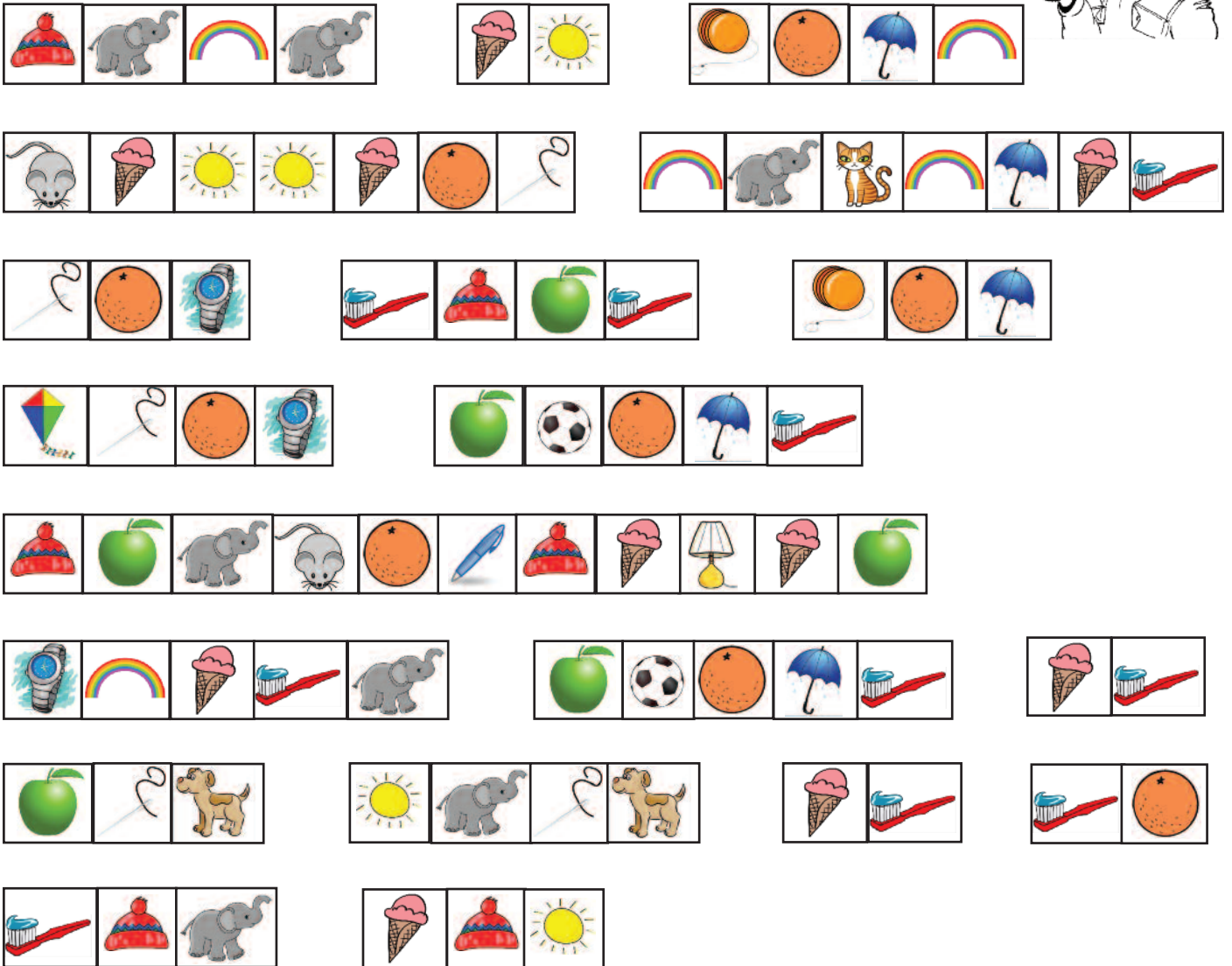
Can you match the following words with their meanings? We have started you off!

- | | |
|-----------------|--|
| 1. Port-a-cath | A) Another word for injection. |
| 2. Internal | B) A level of haemophilia when a person has between 1% - 5% factor levels. |
| 3. Infusion | C) If haemophilia is not spontaneous then it is _____. |
| 4. External | D) A daughter of a man with haemophilia will not have haemophilia herself, but will be a _____. |
| 5. Moderate | E) A device inserted under the skin to allow you to take injections. It is also known as a Freddie. |
| 6. Factor | F) When a bleed happens inside the body it is known as an _____ bleed. |
| 7. Target Joint | G) People with haemophilia take this to help prevent and treat bleeds. |
| 8. Inherited | H) When you cut yourself and bleed on the outsider this is called an _____ bleed. |
| 9. Carrier | I) place in the body where a bleed occurs several times and causes damage. |

Code Cracker



Every good recruit knows that sometimes you need to code your messages. I have coded a message for you below, use the code cracker above to read your message!



My Bleed hiSTORY

Having a bleed is sore and painful. Sometimes people do not know how much you have been through. We have put together a Bingo Board for people with haemophilia to show some things you go through that many people will not. On the board below, mark the squares which apply to you. Two squares are in colour - these are special, when you cross these off show it to your parents and tell them to contact the I.H.S. and we will send you out a special prize.

Bring your workbook to the IHS events and show us how many boxes you have crossed off!

I've been to Barretstown with my family.		I have a sibling with haemophilia.		I've missed a day of school because of my haemophilia.		I have a family member with haemophilia.
	I can self infuse.		I have been to OLCHC or CUH.		I have been in hospital overnight.	
I have a Freddie.		I am the first person in my family to have haemophilia.		I have had my Freddie taken out.		I take good care of my teeth.
	I have been to Barretstown by myself.		I have been to an I.H.S. weekend.		I like swimming.	
I keep a record of my factor for the hospital.		I have taken factor in another country.		My friends know I have haemophilia.		I always take factor before I play a sport.
	I get my factor through my Freddie.		I am on prophylaxis.		I help my Mam and Dad with my infusions.	
I always tell a grown up when I have a bleed.		I get my factor in my vein.		I wear my helmet when I go cycling.		I have finished the I.H.S. workbook.

Answers:
Crossword: Down: 1) Factor Soldiers, 2) Injection, 3) Tourniquet, 4) Prophylaxis, 7) Bleed
 Across: 3) Treating, 5) Compression, 6) Code, 8) Clot, 9) Freddie
Family Tree: 1a) Mary, 1b) Michael, 2) Three, 3) Eight, 4) Great, great grandson, 5) No, 6) Yes, 7) False - there is only a 50% chance he will have haemophilia, 8) False - there is only a 50% chance she will be a carrier.
Word Match: 1 - E, 2 - F, 3 - A, 4 - H, 5 - B, 6 - G, 7 - I, 8 - C, 9 - D.
Code Cracker: Here is your mission recruit, now that you know about haemophilia write about it and send it to the IHS.



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Artwork by Ger Hankey

