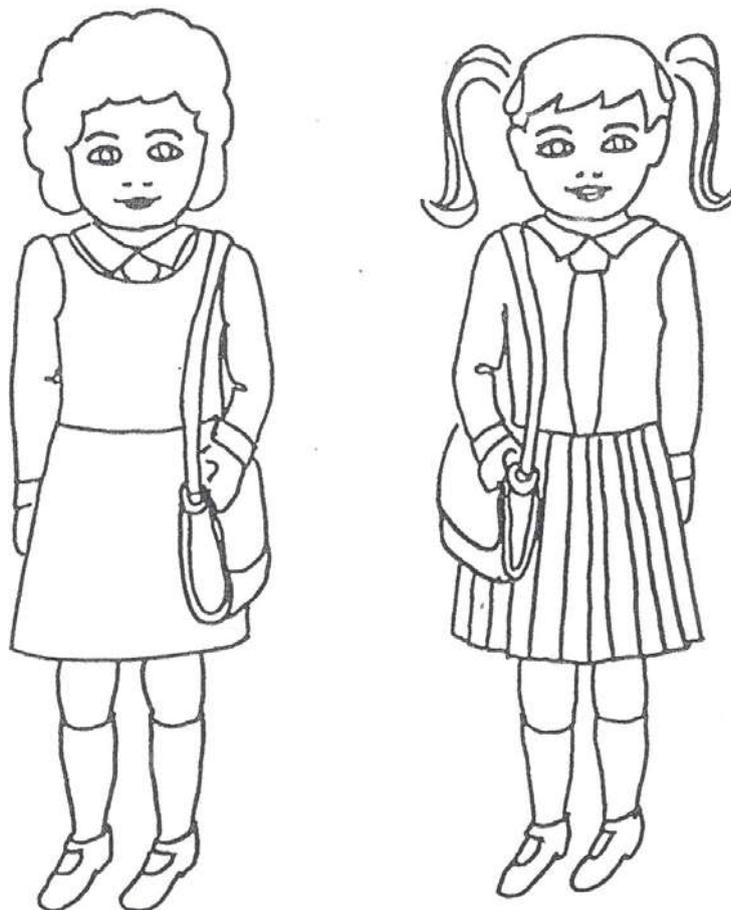




‘Polly’s Best Friend’

A booklet for girls under 10

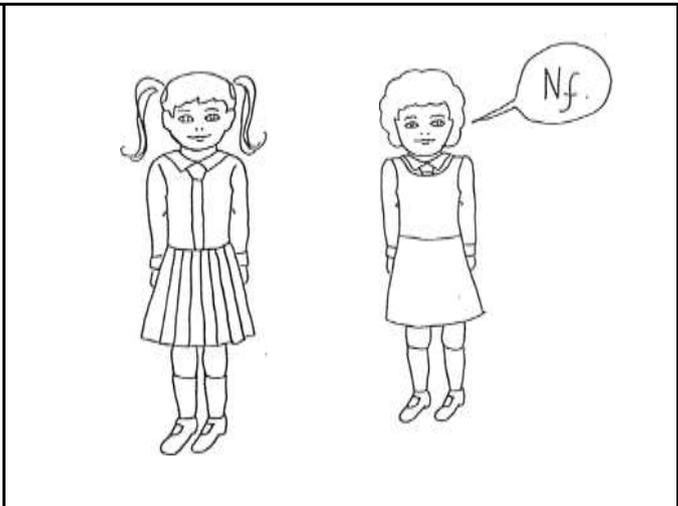
Specially written by Gina Malyon



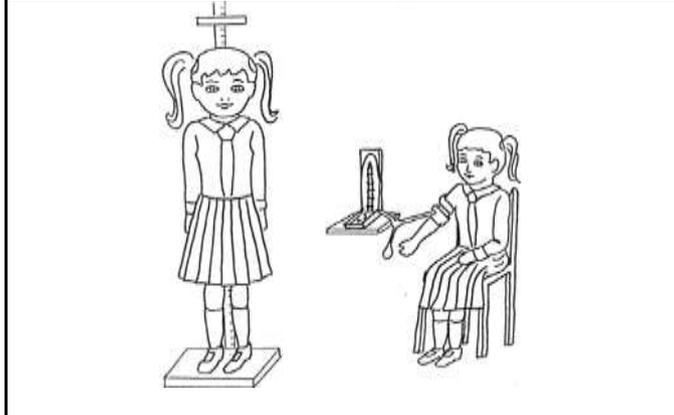
Polly is eight. She has a best friend called Jane.
Polly and Jane go to the same school.



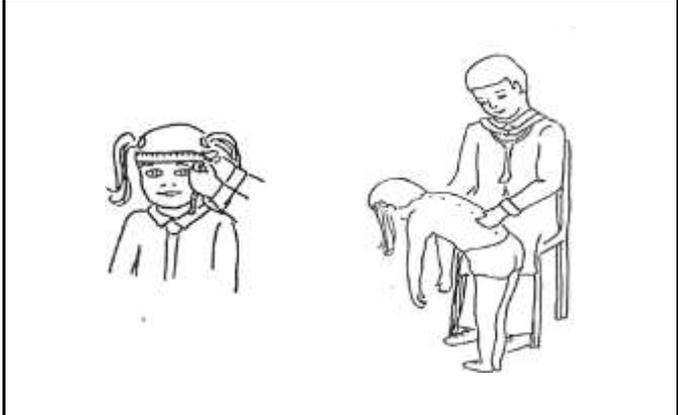
1. Sometimes Jane has time off school to go to the hospital to visit the doctor.



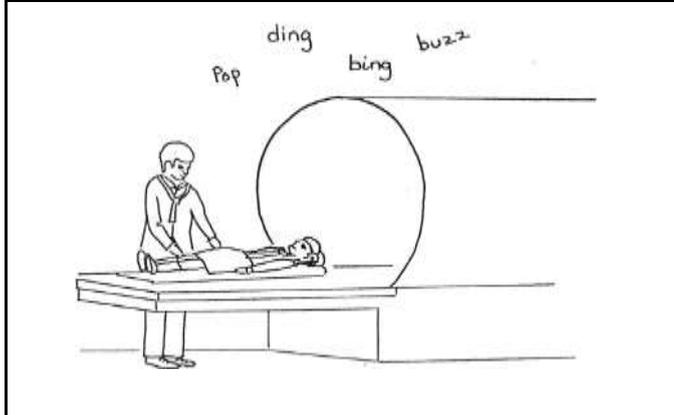
2. Jane visits the doctor because she has something special. It is called Neuro-fibro-matosis. Polly calls it NF. This is easier to say.



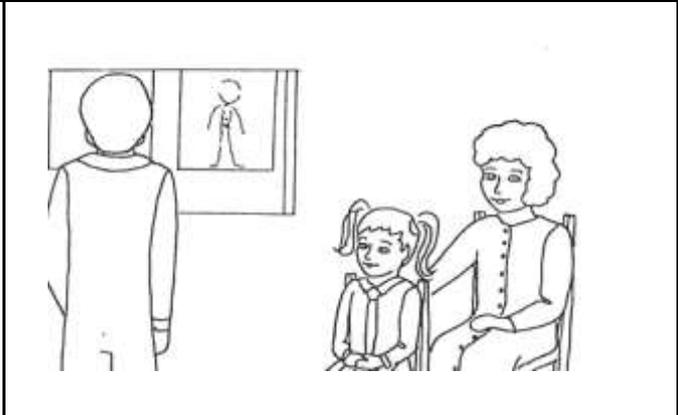
3. Jane is measured to see if she has grown. The doctor takes Jane's blood pressure — he puts a band around Jane's arm, the band fills with air and squeezes her arm.



4. The doctor measures Jane's head. Sometimes Jane has to take some of her clothes off. The doctor can then see if her spine is growing straight.



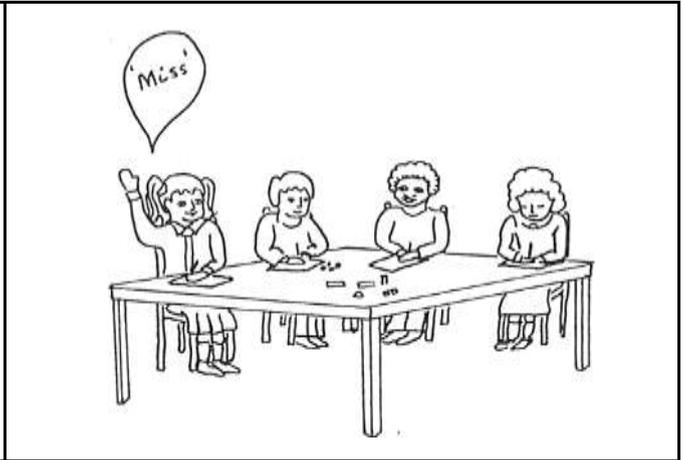
5. Sometimes Jane has a scan. She goes for a ride on a big machine with a tunnel inside. The machine makes funny noises and takes pictures of Jane's body.



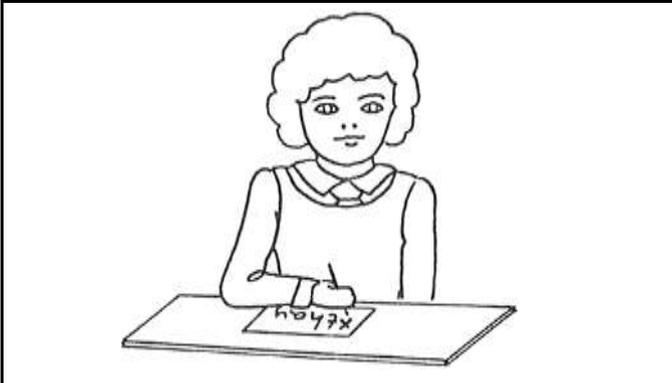
6. The doctor looks at the pictures to see how Jane is growing. Jane thinks the doctor is funny.



7. The doctor asks Jane and her mum lots of questions. Jane's mum explains anything Jane does not understand.



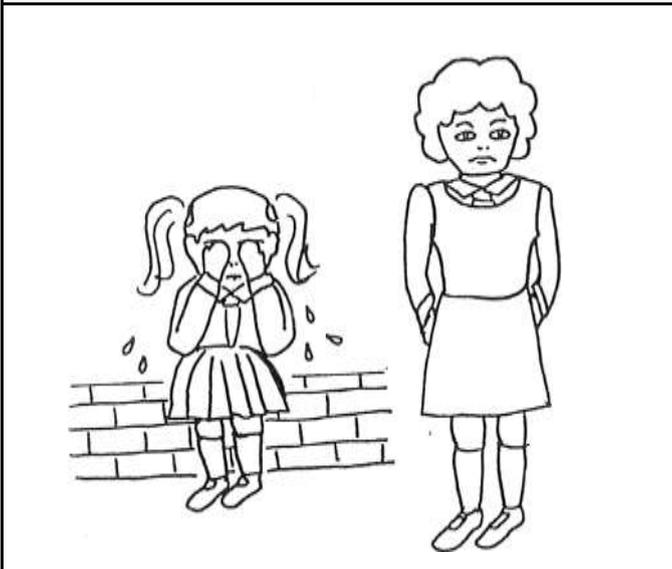
8. Like other children at school, Jane sometimes has problems with her school work.



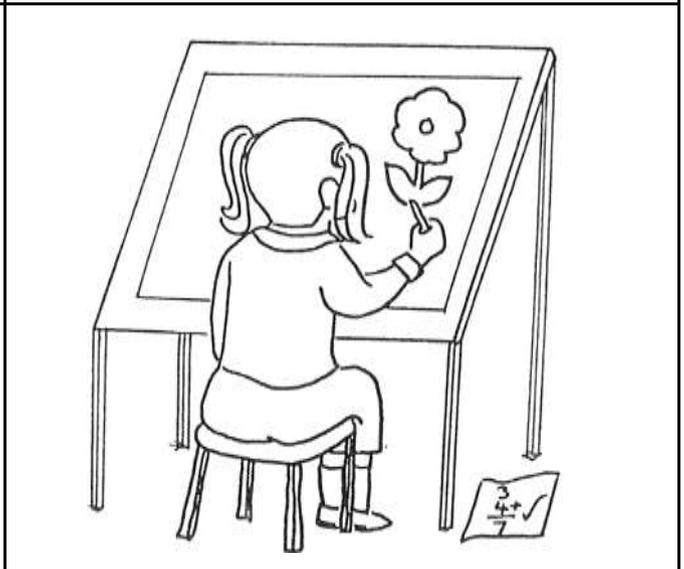
9. Polly knows what this is like. She has problems with her spellings.



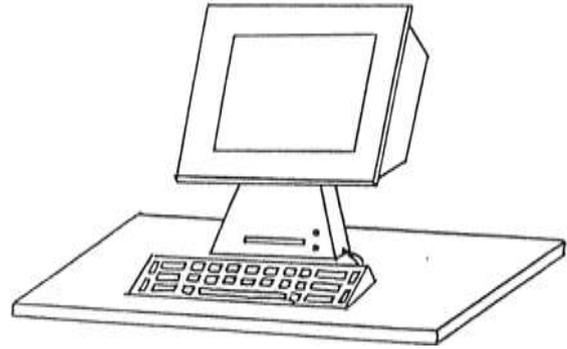
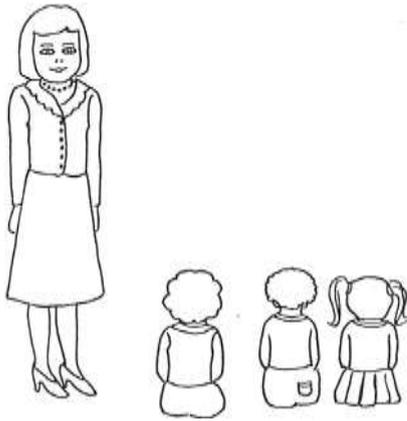
10. Sometimes other children tease Jane if she drops the ball or says the wrong word.



11. This upsets Jane and Polly feels very angry. Polly and Jane tell Mrs Green about the teasing.



12. Jane is very good at number work and draws the best pictures in the class. Polly wishes she could draw like Jane.

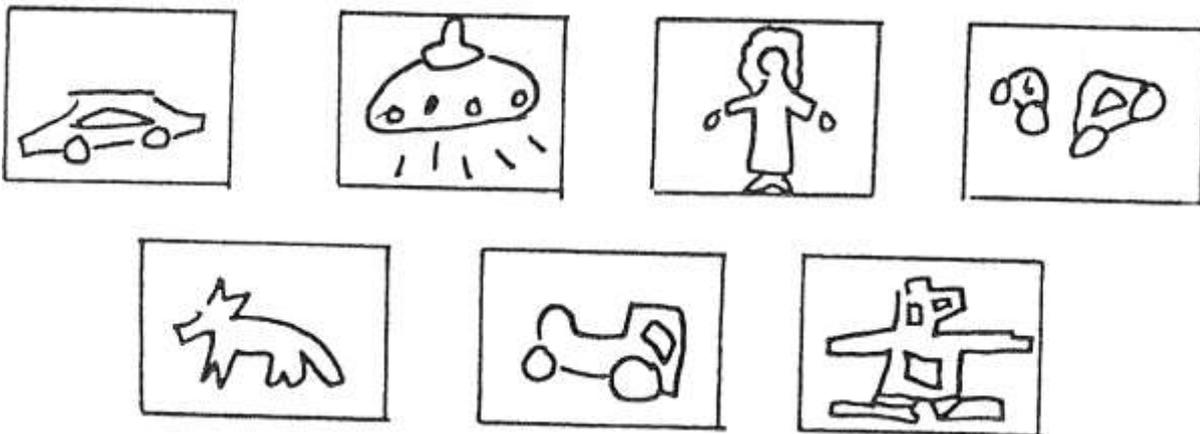


13. On Monday morning Mrs Green, the headmistress, announced that there was to be a drawing competition for all the local schools.

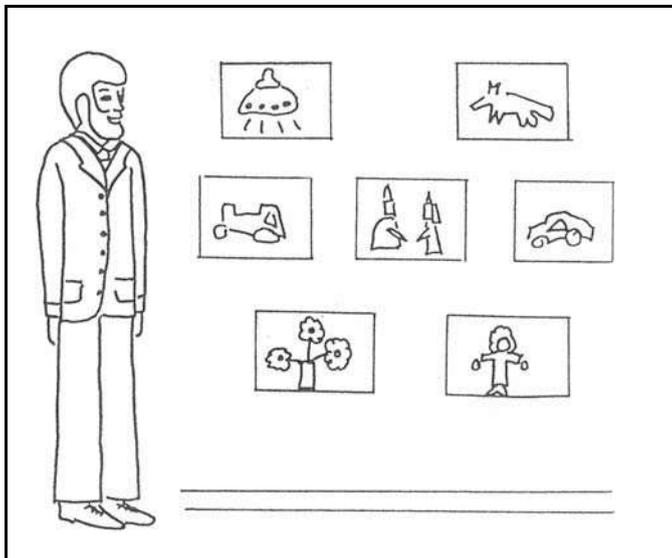
14. The prize was to be a computer for the school that won.



15. Monday afternoon all of Polly and Jane's class settled down to draw their pictures.



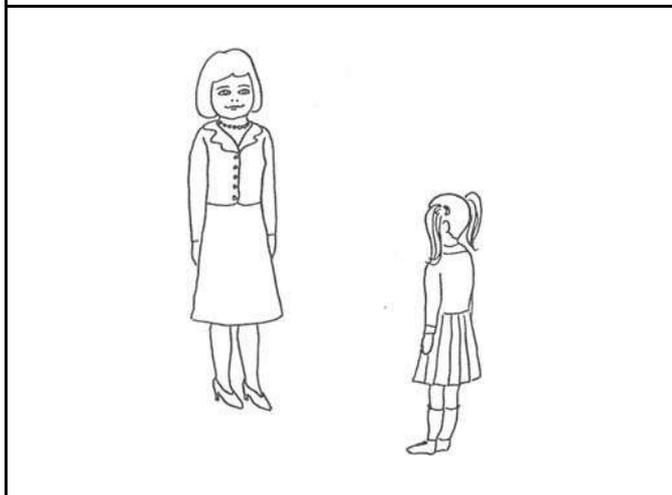
16. There were lots of pictures — there were cars, spaceships, robots, animals and ladies in long flowing dresses.



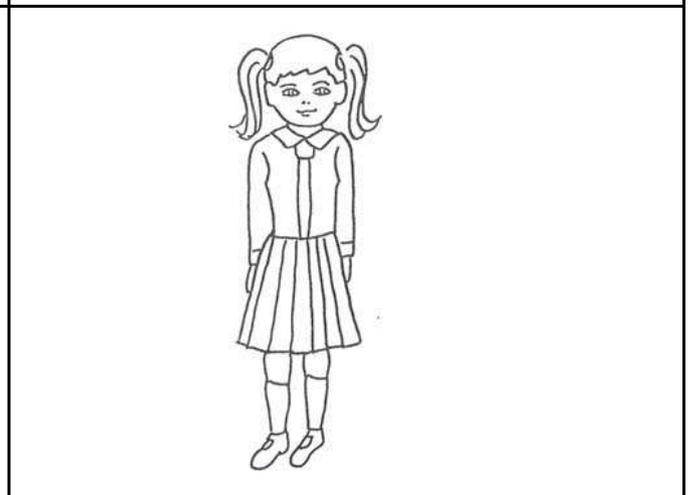
17. The big day arrived to choose the winning picture. A man from the computer company came to choose the best picture.



18. He chose Jane's picture. All of Jane's class cheered and hugged her. Jane just stood there with a big smile on her face.



19. Mrs Green told Jane that the whole school was very proud of her for winning the competition.



20. After school Jane told Polly that even if she is teased and has to work hard at school, having NF wasn't so bad after all!

Helpline Team
Nerve Tumours UK Helpline

helpline@nervetumours.org.uk
07939 046 030

Nerve Tumours UK
44 Coombe Lane, London SW20 0LA

nervetumours.org.uk



What is Neuro-fibro-matosis?

Our bodies are controlled by our brains and things like little wires called nerves: they help us to see and hear and feel and move and learn.

How we are made is controlled by things called genes which we inherit from our parents. The genes are the code for building human beings. Sometimes there is a mistake in the code and something goes wrong. Sometimes the genes go wrong all by themselves before the baby is born. Neuro-fibro-matosis (NF, 'enn-eff') is caused by one of these mistakes and affects the nerves.

People with NF usually have six or more marks like birth marks which are the colour of milky coffee and they are called café au lait patches. A lot of people have one or two of these marks anyway. People with NF sometimes have difficulties with learning, writing, sums or remembering things which others don't have, even though they are just as clever as anyone else. Sometimes NF can make people not very good at games or catching a ball but, like Jane in the story, they may be especially good at some particular thing. Sometimes other things go wrong too but more often people with NF are able to lead a normal life like anyone else although they have to have check-ups with the doctor now and then.

There is a Charity for people with NF which is able to tell them all about NF and help them if they have special problems (for contact details, see below). Nerve Tumours UK also raises money to help doctors find a cure. There are doctors all over the world working very hard on this and we know that one day they will succeed.

Please seek further information from www.nervetumours.org.uk, or contact our helpline on the details above.

Nerve Tumours UK has taken reasonable care to ensure that the information contained in its publications is accurate. Nerve Tumours UK cannot accept liability for any errors or omissions or for information becoming out of date. The information given is not a substitute for getting medical advice from your own GP or other healthcare professional.

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