

ZAC'S PLAY DAY



JOIN IN!
Colouring, stickers
and brainteasers
with Zac

Created for the spinal muscular atrophy (SMA) community

Illustrated by Charles Santoso

Can you spot Zac's pattern? Colour it in!



Spinal muscular atrophy (SMA) is a rare genetic disease that affects the nerves that control muscle, impairing the motor function of tens of thousands of people globally.

Some people with SMA are unable to sit, while others have difficulty walking. Some people have problems breathing, eating and performing everyday activities. SMA can affect babies, children, teens and adults – and everyone experiences the disease in different ways. SMA does not affect an individual's ability to learn.

“Zac's Play Day” relates the experiences of a child with SMA.
It is not meant to represent the experience of everyone living with SMA.

This story is intended to aid in education and awareness of SMA, and to help explain the reality of living with the disease, including the limitations it may involve and the abilities people with SMA may have.

We dedicate this story to people with SMA, their families, caregivers, healthcare professionals and SMA advocacy groups all over the world.

ZAC'S PLAY DAY

About the contributors

Zac's Play Day is brought to you by Biogen in collaboration with the advocacy organisations Cure SMA and SMA Europe, and SMA experts Dr. Robert Graham and Dr. Crystal Proud. Many thanks to those who helped develop the content and for their shared commitment to the SMA community.

For more about SMA, please visit www.lebenmitsma.de, www.CureSMA.com and <https://www.sma-europe.eu/>



About the illustrator

Charles Santoso loves drawing little things in his little journal and dreaming about wondrous stories. He gathers inspiration from his childhood memories, and curiosities he discovers in his everyday travels. He lives and works in Sydney, Australia. You can find out more about him at CharlesSantoso.com.

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Which sticker
from the sticker pack
might fit best here?





“Rise and shine, my loves!” Zac’s mum shouted from down the hall.

Zac opened his eyes to a bright, new day. As he waited for his mum to lift him up, he watched as his older brother Ziggy leapt out of bed and trampled around the room getting ready for the day ahead. Today, his brother was taking him to the playground.



Mrs. Zebra gave a hearty bray when she saw Ziggy’s Tshirt. “Honey, what have I told you about wearing spots with stripes?!”, she laughed.

Help Ziggy
get dressed and
colour him in.

She scooped her hooves carefully under Zac's back and helped him into his wheelchair.

She then took a fresh pair of socks and pulled them on for him.

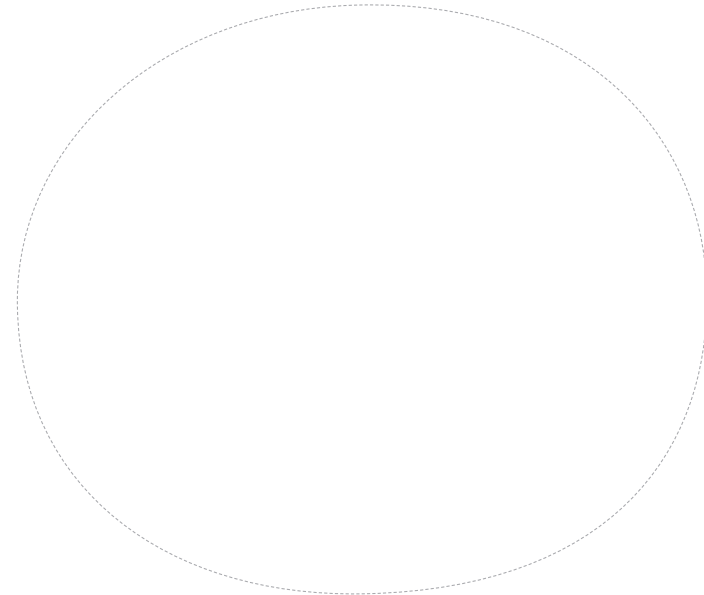


"Let's not forget to do your mane," she said with a smile.

"I want a mohawk today, Mum!" Zac bellowed, as Mrs. Zebra brushed his mane.



Can you find a sticker that fits?



"Eat up, my loves!" Zac's mum said. "You don't want to miss the herd!"





Zac and Ziggy liked to play hide and seek.
But today, they wanted to try something new.

Zac wondered if they should join the elephants swapping trading cards, the animals playing tig in circles around the fountain, or maybe the gazelles who had brought the latest video game.



Spot the difference! 17 things are
different in the picture on the right.
Compare it with the picture on
the left and mark the differences.

Zac felt a tap on his shoulder. He turned his head to see the belly of a giant giraffe standing in front of him.

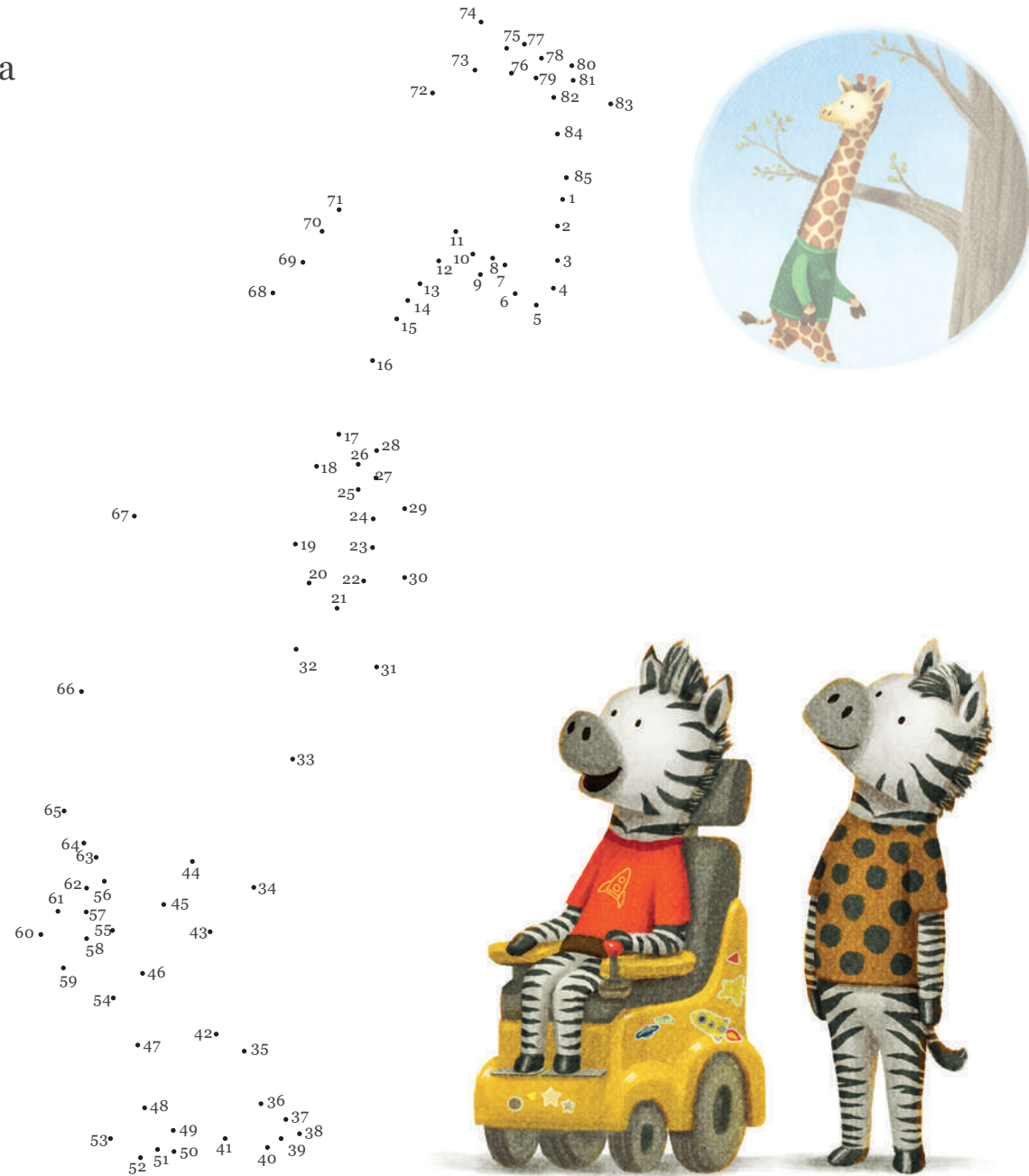
“Did you hurt yourself?” the giraffe asked from up high, gesturing towards Zac’s wheelchair.

“I know what it’s like! I had an accident myself last week,” he said, pointing to his long neck.

“Nah, I’m not hurt,” Zac said. “I have SMA.”

“S-M-what?” the giraffe asked.

What animal are Zac and Ziggy talking to?
Join the numbers from 1 to 85.



Zac noticed several other animals approaching him and Ziggy, and they all looked as curious as the giraffe did.

Ziggy gave Zac a nod of encouragement as he cleared his throat and said to the group that had formed around him: “I have spinal muscular atrophy.”

“What’s that?” asked the ostrich. Zac looked around to the group.





“It’s pretty rare.”



And it means my body develops differently from your bodies



Usually muscles get stronger as we grow up, but with SMA, they get weaker.”



“Did you catch it from someone?” the elephant asked. “No, I was born with it,” Zac said. “When I was a baby, my parents noticed I was a bit weak. I had trouble sitting up and my legs weren’t very strong, so they took me to the doctor, who told them I had SMA.”



Colour in Zac and his friends.



“Does everyone with SMA use a wheelchair?” the hippo girl asked. Zac thought about his other friends with SMA, Ping and Oliver. “No, not everyone,” he said. “SMA is different for different people. Some are older, some are younger, and some need more help moving than others.”



“We sometimes need help with other things too, and for this, there are lots of gadgets and equipment,” Zac continued, “like a special tube that can help with meals or machines to help us with breathing and coughing.”



A large group of animals had gathered around Zac and Ziggy by now, all listening closely. Encouraged, Zac proudly went on with his story.

“I even have a special team that look after me”, he said.
“I call them my SMA squad. There’s a doctor who checks my muscles and nerves. And another member who stretches my muscles so that my body stays flexible. One more to make sure I have a proper diet, and a doctor who keeps my breathing muscles as healthy as possible.”



Is there a sticker
for this?





You can colour
in the ball.

There was a sudden commotion on the other side of the
playground. "Our ball!" shouted the meerkats.

One by one, all of the animals able to hop high took turns trying to catch the ball.

The frog went first but didn't even come close.



Then it was the gazelle's turn. She took a running start and sprang into the air. No luck.

Which sticker fits where?



Everyone turned to the giraffe.
"Sorry, friends, I can't help you.
The doctor says I have to rest!"



“Don’t worry, we got this,” said the elephant, as he stretched out his trunk for the meerkat to climb up.

Then he pointed his long nose as far as he could towards the ball.

Even with the meerkat’s arm outstretched as far as it would go, they were still a few centimetres short.

You can stick the ball here.



Everyone was so busy that nobody saw Zac nip over to the other side of the fountain. He had an idea.



Suddenly the jet of water became smaller and the ball fell down.



All the animals looked around in amazement and saw Zac at the fountain's OFF switch. He was smiling.

“When you have SMA, you use the strongest body part you’ve got ... your brain!”
The animals cheered.



The elephant wobbled over to Zac. “Hey, we’re heading over to the watering hole after this. Want to come with us?”

What term are we looking for?

Find the letter needed from every item below.



1st letter



1st letter



2nd letter

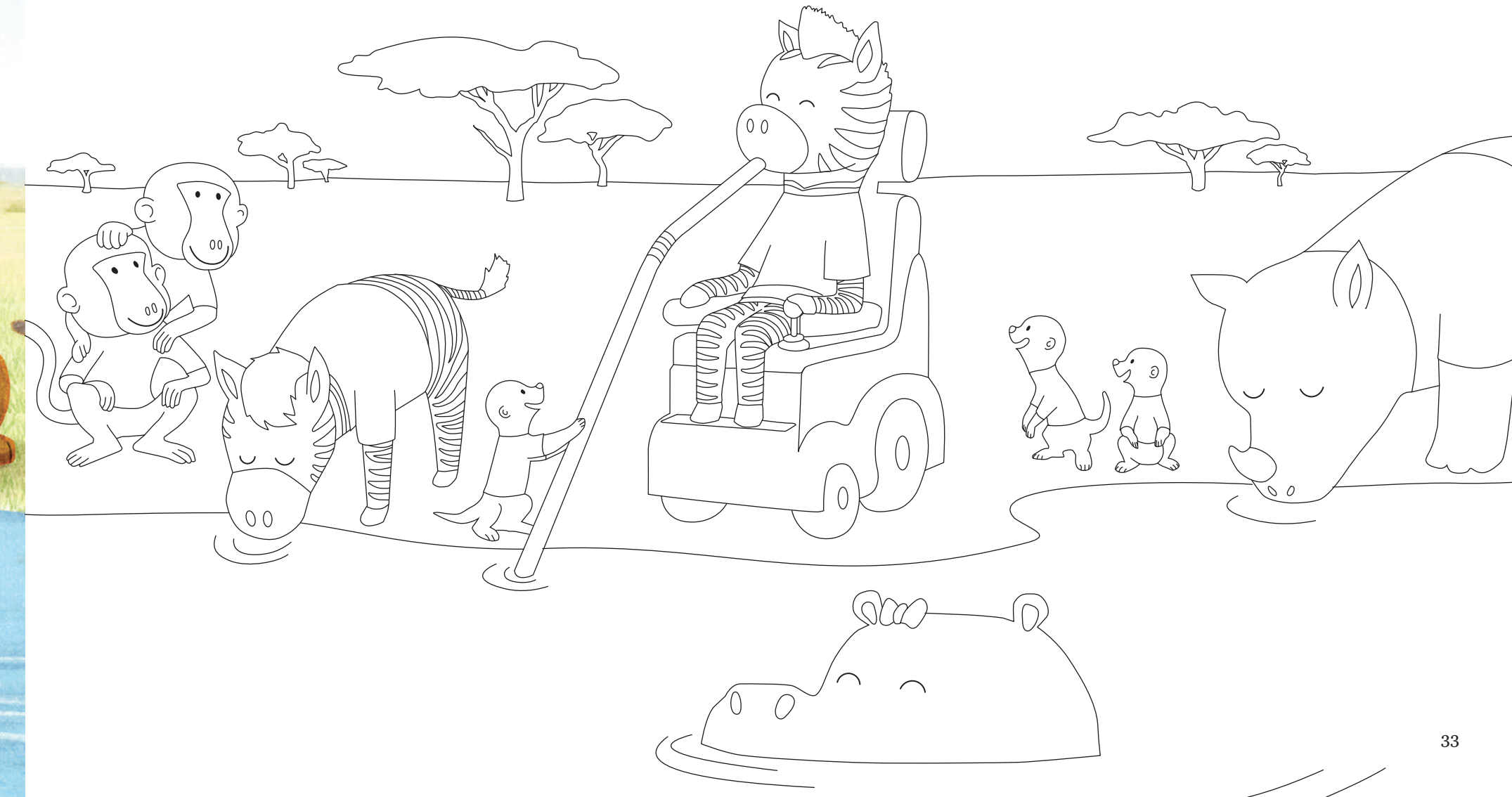
= _____



You can find the solution on page 36.



Oops!... did someone run out of ink?



WORDPUZZLE

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A K J L E U O P Ö Ä P Z K B F P Ä P U K L P T U I I R Ö O

The following words are hiding in this puzzle:
 Can you find them? Search horizontally and vertically!

WHEELCHAIR, SMA, ZAC, MUSCLE, FRIENDS, PAINTING, BALL, TEAM, DOCTOR,
 ZEBRA, TOUR, PLAYGROUND, GIRAFFE, PLAY



MORE RIDDLES

Word search

PLAYGROUND

You can use the letters in the word PLAYGROUND to make lots of new words: LAY, ROUND, or even DRAGON, LONG ...

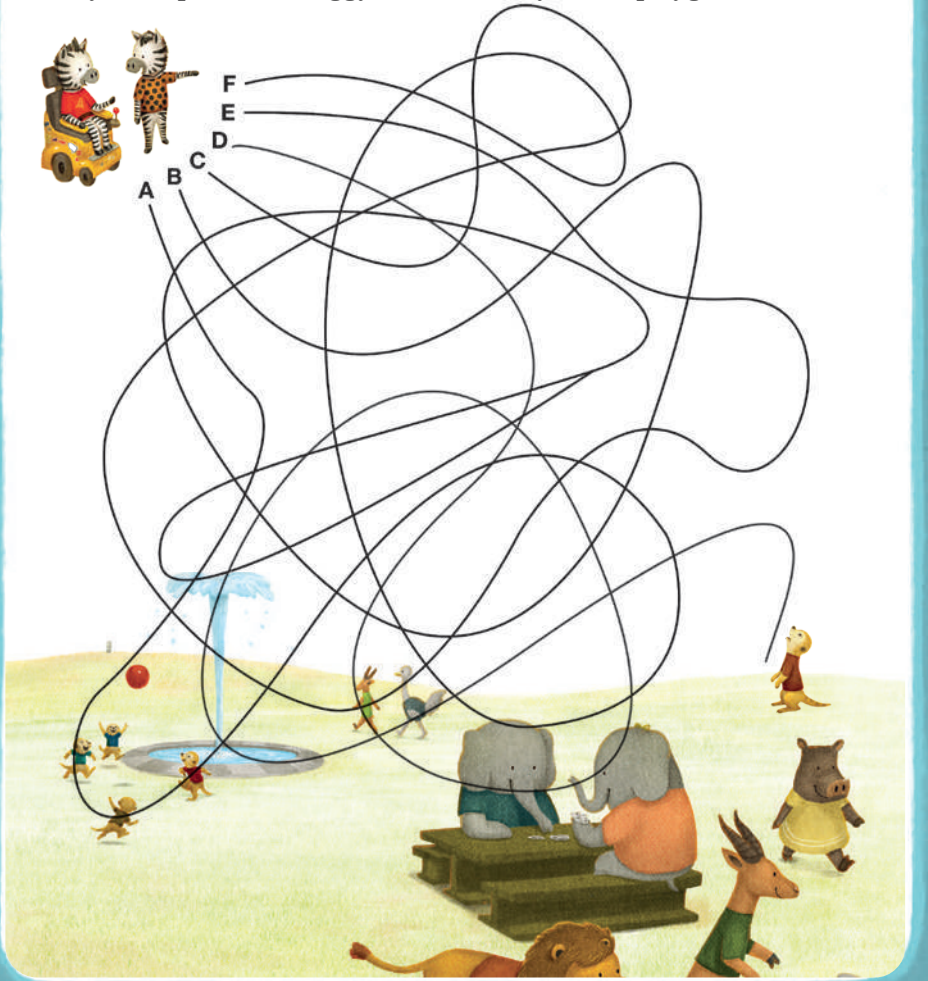
How many can you find?

Find 2 of the same picture



Maze

Can you help Zac and Ziggy find their way to the playground?



SOLUTIONS

You will find all the solutions here.
Just turn the book upside down.



34 You can find the solution on page 34.

Can you find them? Search horizontally and vertically!

The following words are hiding in this puzzle:

WHEELCHAIR, SMA, ZAC, MISGLE, FRIENDS, PAINTING, BALL, TEAM, DOCTOR, ZEBRA, TOUR, PLAYGROUND, GIRAFFE, PLAY

WORDPUZZLE

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Page 34

35 You can find the solution on page 35.

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Maze

Word search

You can use the letters in the word **PLAYGROUND** to make lots of new words: **LAY, ROUND, or even DRAGON, LONG...**

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Find 2 of the same picture

Page 35



33 You can find the solution on page 33.

Spot the difference! 17 things are different in the picture on the right. Compare it with the picture on the left and mark the differences.

Page 13

32 You can find the solution on page 32.

What term are we looking for?

Find the letter needed from every item below:

☆ letter S M A
 1 letter letter
 2 letter letter
 3 letter letter
 4 letter letter

Page 32



Helpful SMA terminology

BiPAP (bilevel positive airway pressure): supports breathing by keeping the airways open. The machine provides positive airway pressure delivered by a mask. It delivers a higher pressure and increased volume when the person inhales. When the person exhales, it lowers the pressure to allow a more regular breathing pattern.

Cough assist device: helps to clear secretions from the lungs. On inhalation, air is blown into the lungs to help them expand. On exhalation, the machine sucks air from the lungs to make the cough stronger.

Genetic disease: a condition that is caused by a change in the DNA of an individual. Most genetic disorders are rare and affect one person in several thousands or millions.

Stomach tube: a stomach tube delivers liquid feedings directly into the stomach via a tube. It is inserted through the abdominal wall during a brief surgical procedure and helps people with feeding problems get enough nutrition, fluids and medicines.

SMA specialists

Neuropaediatrician: Usually the first doctor to see those with suspected SMA. Neuropaediatricians specialise in the diagnosis and treatment of disorders of the nervous system (brain, spinal cord, nerves, muscles) in children.

Nutritionist: important team member for individuals with SMA to support their nutrition and development, as many people with SMA experience over- or undernourishment, which can affect bone strength, growth and mobility

Orthopaedic surgeon: An orthopaedic surgeon specialises in the surgical and nonsurgical treatment of conditions of the bones, joints, and soft tissues. Individuals with SMA may be at risk of certain orthopaedic issues for which an orthopaedic surgeon may recommend assistive devices to stabilise and support the arms, legs and upper body, or appropriate surgery.

Physiotherapist/physical medicine and rehabilitation physicians/occupational therapist: will evaluate an individual's range of motion, muscle strength, and mobility to assess need for stretching exercises and strength training in SMA. They can also recommend exercises or devices to help an individual maintain the best posture for breathing and eating.

Lung specialist/pulmonologist/critical care physician: doctors with specific expertise in the treatment of diseases of the lungs and airways that may require treatment with special medicines or equipment.





Zac and Friends

Stickers for the “Zac’s Play Day” activity book.
Find the right place to put the stickers.



Zac and Friends



Stickers for the “Zac’s Play Day” activity book.
Find the right place to put the stickers.

