

RISING



Bread, Community
and Achondroplasia

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READER'S COMPANION





FOR ADULTS READING TO YOUNGER AUDIENCES



Did you know there are *hundreds* of different types of bread, each with their own set of ingredients? While recipes outline the ingredients and the amount used, every baker makes it uniquely theirs.

Just like bread, people grow up with different experiences and it's these "ingredients" that make each person one of a kind.

These ingredients can look like family and friends, or even schools and communities. They can come from moments of hardship just as much as from moments of joy.

For kids with achondroplasia, it's no different—they **adapt, innovate** and **learn** on the go, as any child will.

Every page of the Rising Love book is full of details that can be used to start a conversation around different aspects of growing up with achondroplasia.

There are adaptations, family and sibling dynamics and visual metaphors to explore with your child, their friend group or school and others in your family's community.

Using this material as a guide will help you turn Rising Love into an **educational experience**, providing more detail around the condition of achondroplasia, including metaphors, conversation starters and activities to help explain and engage with audiences of all ages.

Meet the

Meet Sofia

8 years old

"The best part about people is getting to show them I care!"

Personality

Sofia loves animals and helping others. She is most comfortable in her home where it's quiet and she can spend time with her mum.

Mother

34 years old
Does not have achondroplasia.

Talking Points



Family

Sofia's mum tries to provide a supportive environment to help Sofia build independence and confidence in her ability to adapt how and when Sofia feels it's necessary.



Adaptations

Sofia also has many different types of adaptations throughout her home. Stools, low furniture, light switches and other items can help people with achondroplasia stay independent in a world that's usually made specifically for people of average stature.



Specific Challenges: Sleep Apnoea

Sofia has achondroplasia, which causes the bones in her face to grow in a different way. Sometimes, this can make it difficult for air to get to her lungs, so she uses a machine made to help her breathe while she sleeps. This is called a CPAP or BiPAP machine.



Unique!

Only 1 of every 25,000 kids is born with achondroplasia! That means Sofia is 1 of only around 250,000 people in the world!

Meet Leo

10 years old

"My brother is the coolest person I know! After Grandma."

Personality

Leo loves reading, his grandma and playing football with his older brother, Matt. He gets anxious sometimes and can worry, but Matt has experience dealing with anxiety, so both have learned ways to support one another.

Brother - Matt

18 years old
Has achondroplasia.

Father

40 years old
Does not have achondroplasia.

Talking Points



Family

Leo's older brother Matt has achondroplasia, but Leo and their dad do not. Did you know 80% of kids with achondroplasia are born to parents of average stature? It can be random!



Adaptations

Matt can drive with specific adaptations. A pillow for back support, a raised seat and some pedal extenders can make getting around as accessible as it is for someone without achondroplasia.



Specific Challenges: Mental and Social Health

Mental and social health are just as important to children with achondroplasia as the management of physical health. Leo and Matt are affected by anxiety differently, but Matt can help Leo by teaching him techniques for self-care that he has learnt when wrestling with negative feelings.



Unique!

Just like daily routines, every family has a different style of adapting their homes for achondroplasia. Because Leo doesn't have achondroplasia, he finds himself having to adapt to the tools Matt uses!

Meet Haruki

10 years old



"I don't like croissants... Just kidding, I LOVE croissants!"

Personality

Haruki is a ball of energy. He loves people, loves parties and loves playing football. Both of his parents have achondroplasia, so they have a lot of experience with having been short-statured kids themselves! It's helped Haruki become more independent (sometimes, a little too independent!).

Mother

39 years old
Has achondroplasia.

Father

42 years old
Has achondroplasia.

Talking Points



Family

Both of Haruki's parents have achondroplasia, which means Haruki will be able to learn a lot from his parents' experiences growing up.



Adaptations

Haruki's home has some custom adaptations to make it more comfortable for his family to go throughout their day. He also has a favourite step stool he's decorated like a skateboard.



Specific Challenges: Getting Ready

Haruki's shorter arms and legs can make getting dressed and drying his hair more challenging. It doesn't mean he can't! Kids with achondroplasia will find their own ways to do things, even if they don't look familiar or they take more time.



Unique!

Haruki's parents aren't worried because they've been able to meet lots of different doctors with expertise to help support Haruki as he grows up living a healthy, active life.

"Do you like this dress? I made it myself! It has stripes!"

Personality

Emma has a big personality. She loves being the centre of attention to show off all her favourite outfits and will talk your ear off about her two sisters: *"They're both taller than me now, but that's only because they don't have achondroplasia."*

Two Sisters

7 and 16 years old
Do not have achondroplasia.

Father

45 years old
Does not have achondroplasia.



Meet Emma

9 years old

Talking Points



Family

Emma is the middle sibling and the only one in her family with achondroplasia. She has an older sister who was already growing fast when she was born—and now her younger sister is taller than she is, too.



Adaptations

With so many people in the house, Emma's family tries to adapt what they can while Emma takes care of the rest. Her dad stresses the importance "asking when you need help," so Emma isn't shy about telling the people in her life what she needs.



Specific Challenges: Siblings without Achondroplasia

Every child is different, but it is not uncommon for children to begin feeling isolated as they see younger peers and siblings continue to grow quickly throughout childhood.



Unique!

Growing up with two sisters, Emma's had to learn how to hold her own! Different experiences and people are what help shape us into who we are.



DOUGH RISES; BONES GROW

- 1 Besides turning into Grandma's Famous Focaccia, dough can be used as a metaphor to help explain how people end up always being unique.
- 2 It can also be used to help explain the science behind bone growth and what happens differently in the bones of somebody with achondroplasia.



BONES GROW; WE GROW

- ③ More than 90% of the bones in our body start as something temporary called "cartilage" (**the dough**).
- ④ As we grow (**bake**), our bones get longer when cartilage grows and turns into permanent bone (**becomes bread**).
- ⑤ This is how our bones get longer and we increase in height (**rise**).





FGFR3 AND CNP: 2 INGREDIENTS

- ⑥ Like how water and flour are important ingredients for most types of bread, most of our bones have 2 main ingredients: FGFR3 and CNP to help control how these bones end up growing (**rising**).
- ⑦ In these bones, FGFR3 is a type of ingredient that slows bone growth (**rise slowly**), while CNP is an ingredient that makes bones keep growing (**rise steadily**).



FGFR3 stands for Fibroblast Growth Factor Receptor 3
CNP stands for C-Type Natriuretic Peptide



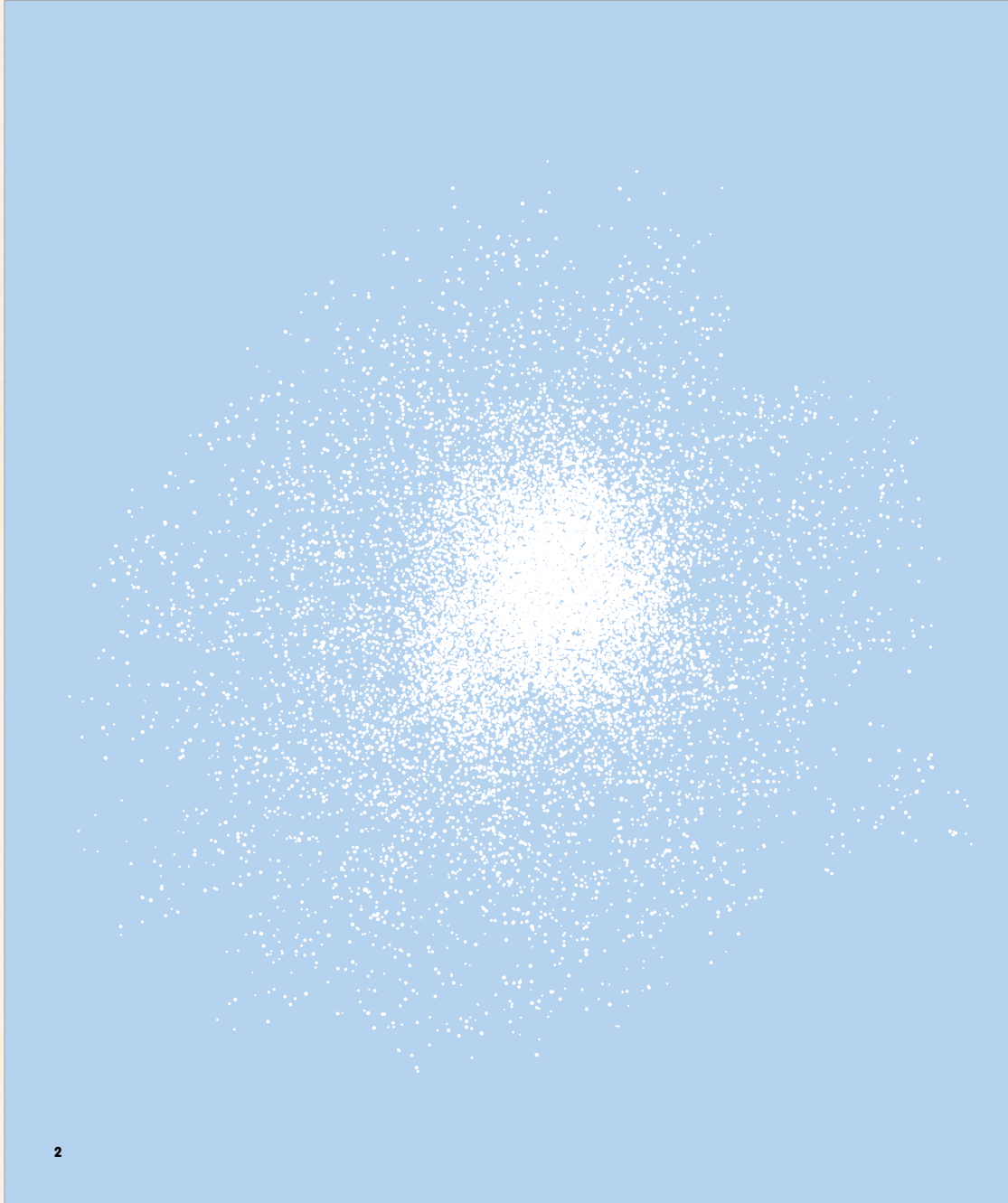
SAME INGREDIENTS; DIFFERENT AMOUNTS

- 8 In the bones of someone who has achondroplasia, the balance of these ingredients is different. They have more FGFR3 than the CNP can keep up with.
- 9 As a result, temporary cartilage (**dough**) is told to stop being replaced by bone (**rising**) sooner than in bones with a closer balance of FGFR3 and CNP (**ingredients**).
- 10 This is how achondroplasia can cause some kids' bones to grow differently than other kids. Same ingredients, just different amounts.





THE FOLLOWING IS A PAGE-BY-PAGE, DIVING INTO THE DETAILS WITHIN "RISING LOVE."



2

Key Legend:



= Health and Emotions



= Adaptations and Management



= Insights to Consider



To Leigh Ann,

You're a sun in the sky and
candle in the dark whose
light will inspire a generation.

Thank you.



CPAP
machine



Sofia

TODAY IS:
**THE
Rising
LOVE
Community
BREAD
Festival!**



Step
stool



Leo

4



Lower table



Haruki



A mattress closer to the floor is common for kids, or even adults, with achondroplasia.

Emma



Sofia, Leo, Haruki and Emma each get to make their favourite bread to share with the entire neighbourhood!

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Sturdy ladders with wide enough steps are great for kids whose arms and legs are shorter.





A lowered bed and step stool make it easier for children with achondroplasia to get in and out of bed.



Sofia is excited to see her friends, but first she needs to make her bed.



Leo is a little nervous because he's never made bread before. His older, super cool brother Matt is going to help.

It is not uncommon for one sibling to have achondroplasia while the other does not.





Shorter limbs can sometimes cause difficulty with clothes when getting dressed.



Emma stayed up late with her sisters, so she needs a little help waking up from Dad.

"Rise and shine, my love,"

Dad says.





There are lots of different types of stools, stairs and other adaptations in the homes of people with achondroplasia.



Sofia wants to pick the perfect bread for her friends. She's been trying to decide all week!



Matt helps make Leo's hair cool.

"It'll help with being nervous,"

Matt says.



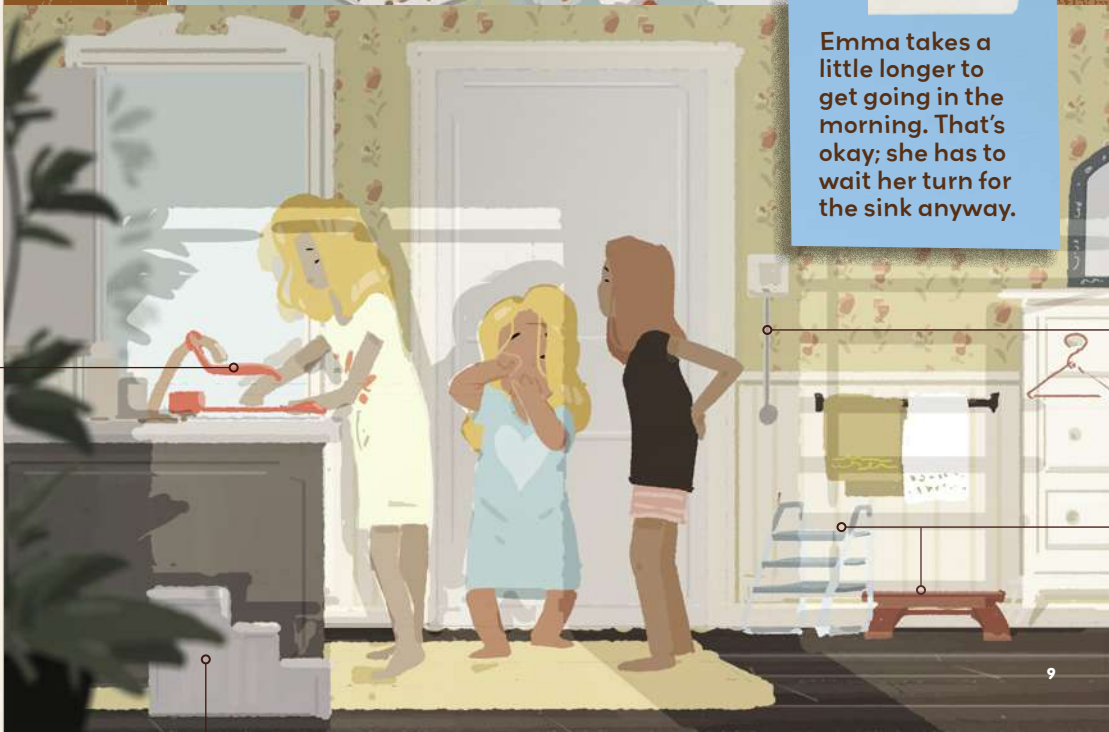
Sink extenders



There are adaptations to make reaching taps easier for people with achondroplasia



Shorter arms can make it harder to reach the top of the head.



Emma takes a little longer to get going in the morning. That's okay; she has to wait her turn for the sink anyway.



Sink extenders



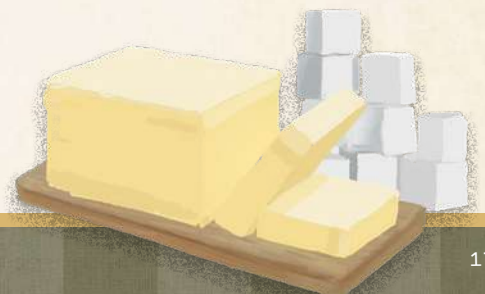
Light switch extenders



Stools

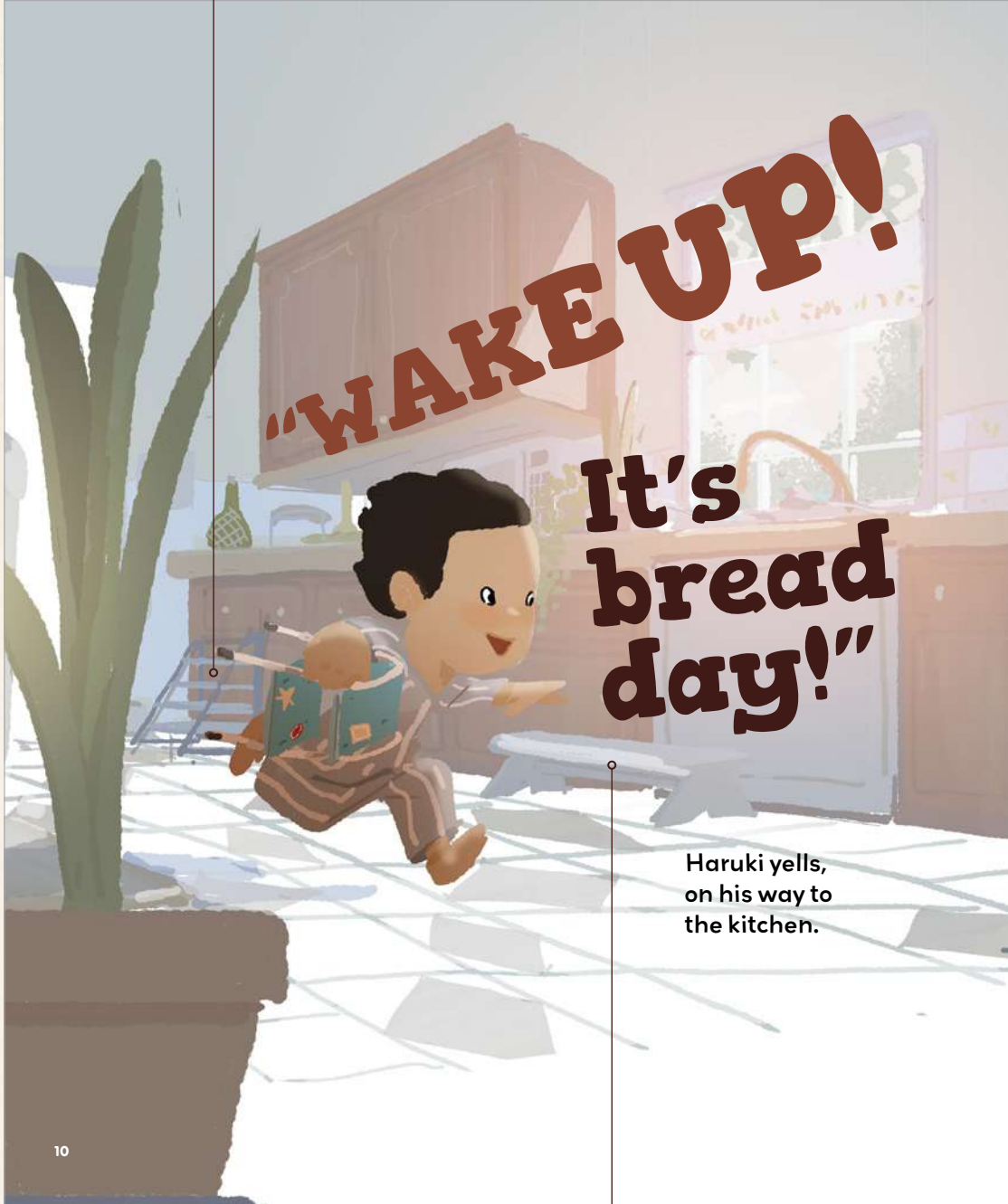


Step stool





Step stool



10



Stool

"What bread did you choose, Sofia?" her mum asks.

Sofia smiles and turns to her mum with the recipe in her teeth!

"Ooo, that's my favourite,"
Says mum.

"I'll start up the clay oven."



Step stool



Light switch extenders



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"Do we really need
that bowl?"
asks Matt.

"It's the one
Grandma
uses!"
answers Leo.

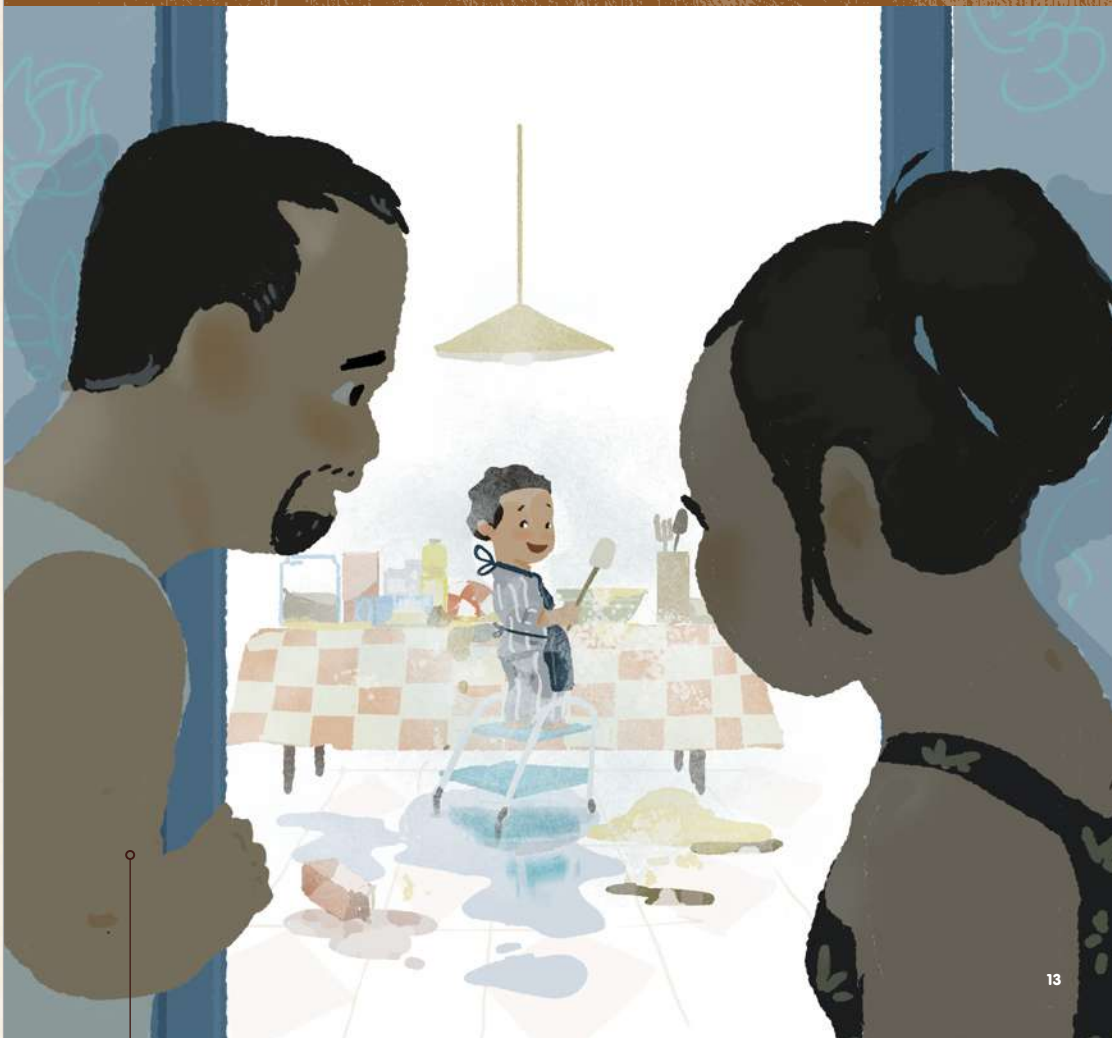
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Anyone can use a stool —
they're not just for people
with achondroplasia!

Haruki was so excited he didn't wait for his parents to get started!

What a mess!



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There are families where the parents both have achondroplasia. That means some houses can be fully customised for people with a shorter stature.





Now that everyone is awake
and in the kitchen, it's time
to make the dough!

Emma is making her
family's famous pretzels.

**"Dad, can you
take a picture
from up high?"**

asks Emma.

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Being comfortable asking for help can help
any child build confidence in vocalising
what they might need assistance with.



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Children with achondroplasia gradually develop their personal relationship to height.



See Discussion Card:

Bones Grow;
We Grow

See Discussion Card:

FGFR3 and CNP:
2 Ingredients



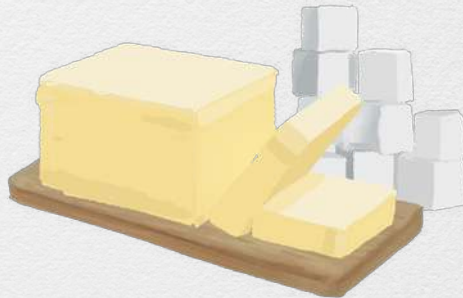
Then, some people add honey and cinnamon.



Or maybe rosemary and garlic.



Some bread uses butter and sugar.



And others use baking soda and salt.



Even when dough has more or less of something, it can still be delicious. That's why there are so many unique types of bread!

See Discussion Card:

Dough Rises;
Bones Grow

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Now that all the dough is made, it's time to put it in the oven!



Oh, no!

Leo accidentally dropped some dough on the floor!



"That's okay,"

says Matt.

"The best bakers probably drop lots of stuff."

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Anyone can be sad sometimes, but siblings and peers can be an important part of a healthy support network.



Haruki and his parents are rolling their dough into croissants.

“Like father, like son,”

Mother says.

Emma loves creating shapes with the dough.



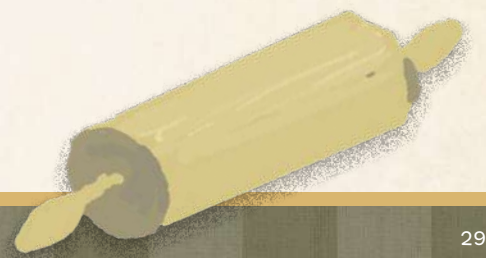
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See Discussion Card:
Same Ingredients;
Different Amounts

Because of the unique ingredients,
if you put two types of dough in
the oven for the same amount of
time, they might rise and grow to be
different shapes, sizes and textures.





Now that the bread is made,
**it's time to go
to the festival!**



Pillow
for back
support



Pedal
extenders

Leo can't wait to learn
how to drive like Matt.

**"Good thing the park is
just down the street!"**

jokes Leo.

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People with achondroplasia can drive with the use of pedal extenders, a higher seat or some pillows and back support.

Every family has a different way of adapting their car — some are even completely customised.



Sofia wonders if she made enough bread.

"Croissants!"



Haruki yells as he arrives.

"My great-great-grandpa taught my great-grandma who taught my grandma who taught my dad who taught me,"
explains Emma.



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"I made cinnamon naan because it makes people happy," says Sofia

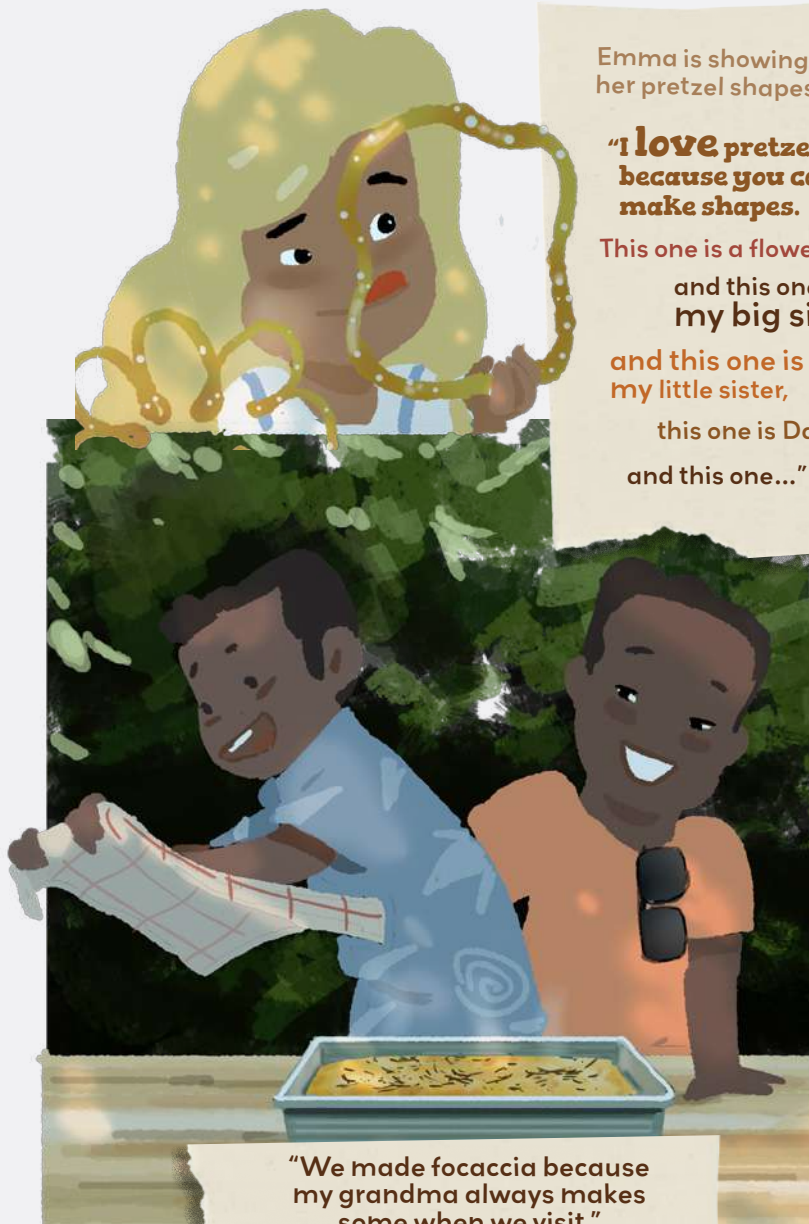
"Oh! And it's my mum's favourite."



"Croissants are the best"

because I could eat an entire basket all by myself!"

Haruki says through a mouthful of bread.



Emma is showing off her pretzel shapes.

"I love pretzels because you can make shapes.

This one is a flower
and this one is
my big sister
and this one is
my little sister,
this one is Dad
and this one..."

"We made focaccia because my grandma always makes some when we visit."

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Matt

Haruki

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Just like bread, every person will grow into who they'll become differently based on their experiences with family, friends, peers, strangers, school teachers and community leaders.

We may all have different ingredients and in different amounts, but that's what makes every person unique and extraordinary.



Emma

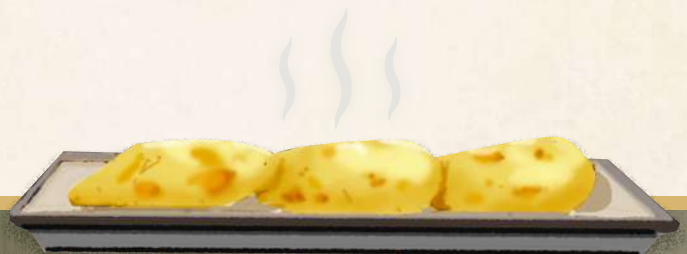
Leo

Sofia

Any type of bread can make people happy.

What makes bread truly special is the way we can share it with our loved ones, friends and communities.

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How can the Rising Love Bread Festival help the people in your life understand achondroplasia?

Meet Sofia, Haruki, Leo and Emma. Four unique kids in families where achondroplasia is just a part of life. Today, our young heroes are each baking their favourite bread to share at the Rising Love Bread Festival.

With beautiful hand-drawn illustrations, dive into the details of the Rising Love world to connect, inspire and educate anyone—no matter how they grow up.

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To learn more about achondroplasia, visit achondroplasia.com.





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