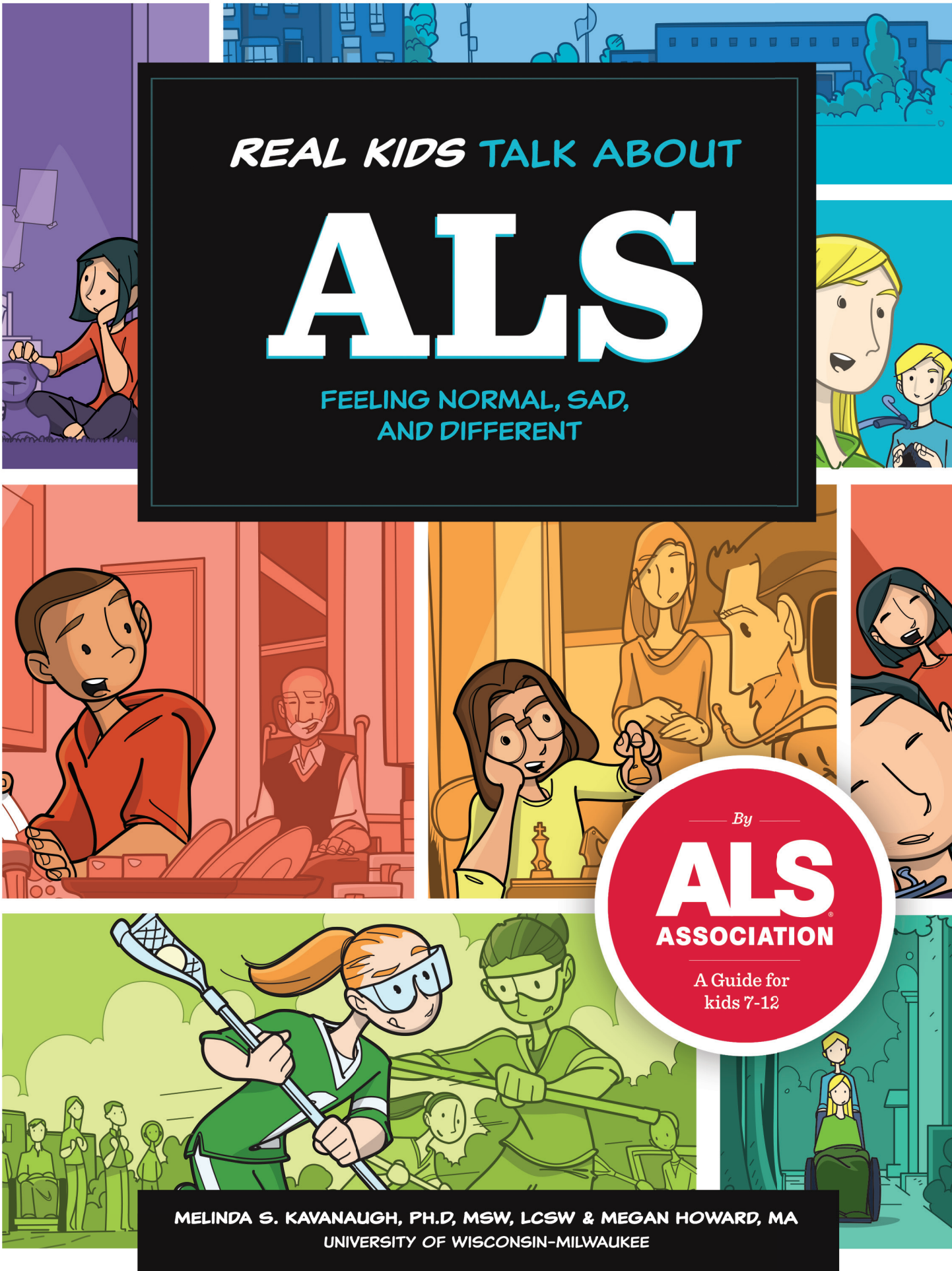


REAL KIDS TALK ABOUT

ALS

FEELING NORMAL, SAD,
AND DIFFERENT



By

ALS
ASSOCIATION

A Guide for
kids 7-12

MELINDA S. KAVANAUGH, PH.D, MSW, LCSW & MEGAN HOWARD, MA
UNIVERSITY OF WISCONSIN-MILWAUKEE

Dr. Kavanaugh is a licensed clinical social worker (LCSW) and associate professor of social work. She has over 15 years' experience in practice and research with families and youth living with neurological disorders. She has published and presented widely in the role children and youth play as caregivers and is one of the few U.S. based experts in her field. In addition to her primary research and program development with The ALS Association, Dr. Kavanaugh conducts research with U.S. and international organizations to develop evidence based supportive and educational programs for young caregivers and their families. Dr. Kavanaugh holds an MSW from Washington University in St. Louis, and a PhD in social welfare from the University of Wisconsin-Madison.

Megan Howard, MA is a research program coordinator at the University of Wisconsin-Milwaukee (UWM). Megan is trained in psychology and child development, and has spent years working on research projects involving children and families. She is currently working with Dr. Kavanaugh on the development of training programs for youth caregivers.

Illustrated by **Phil Gosier**

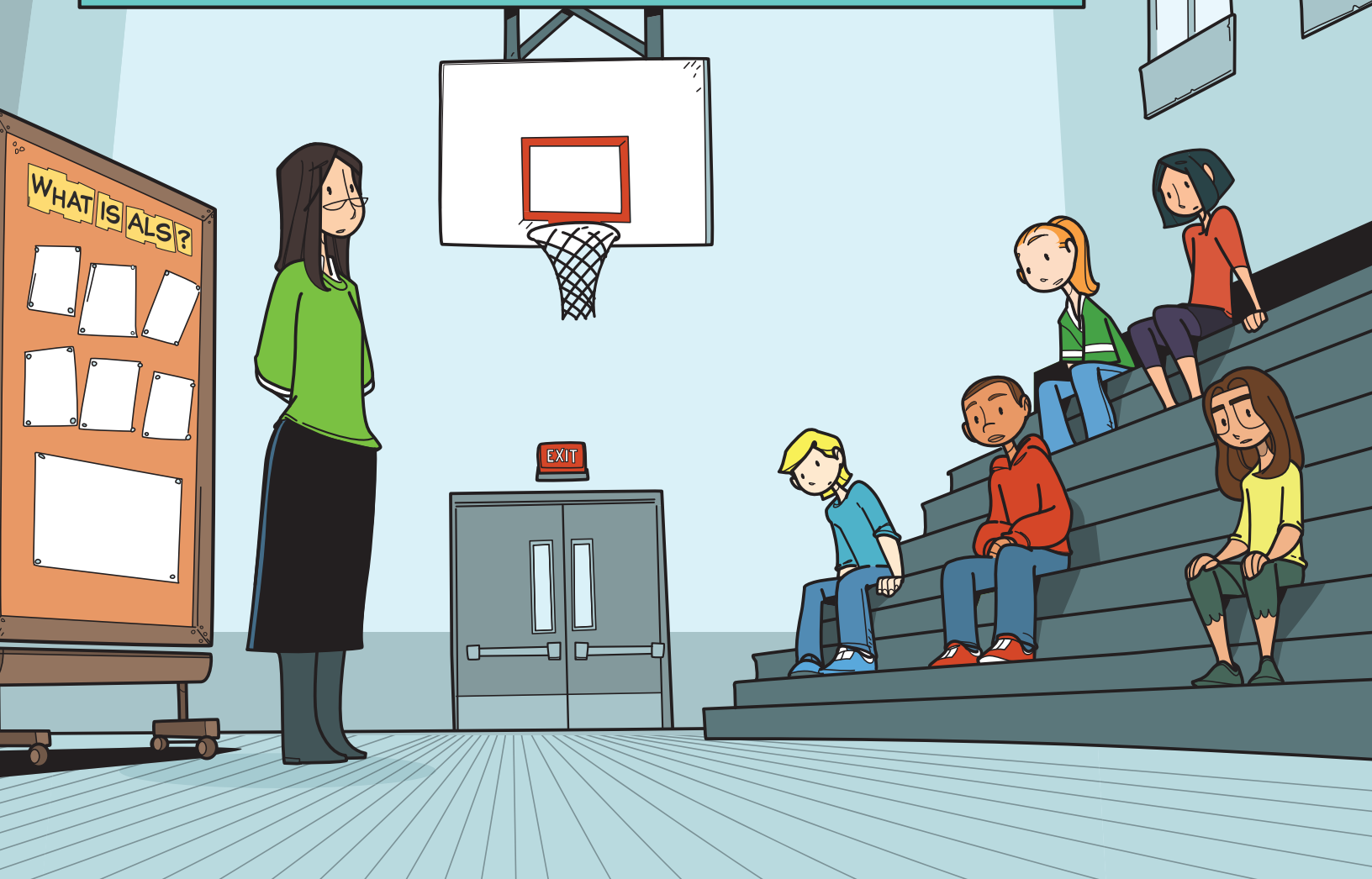
WHY DID WE WRITE THIS BOOK?

ALS AFFECTS ALL PEOPLE IN THE FAMILY – INCLUDING KIDS. THERE ISN'T ENOUGH INFORMATION OUT THERE TO HELP KIDS UNDERSTAND WHAT ALS IS, WHAT ROLE YOU PLAY AS CAREGIVER, AND HOW TO TALK ABOUT THESE ISSUES.

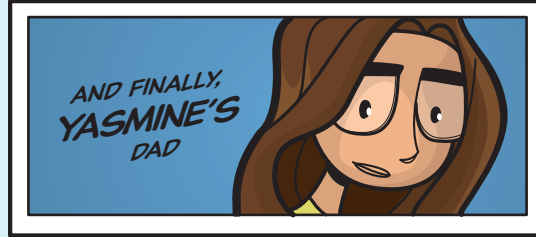
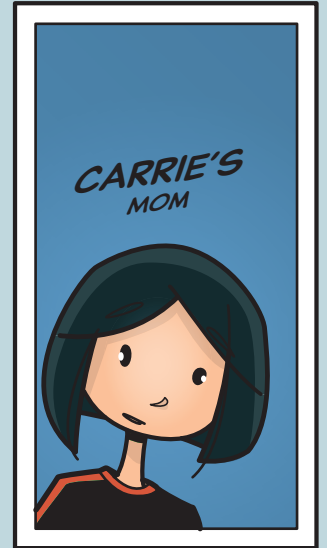
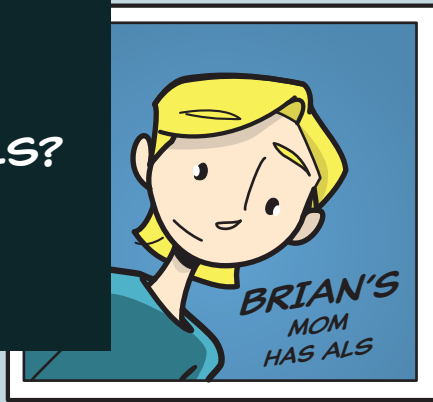
DR. MELINDA KAVANAUGH HAS CONDUCTED LOTS OF RESEARCH WITH FAMILIES LIVING WITH NEUROLOGICAL DISORDERS – INCLUDING ALS. SHE HAS ASKED PARENTS AND KIDS WHAT THEY NEED, AND WHAT THEY KNOW OR DON'T KNOW ABOUT ALS.

ALL THE STATEMENTS BY YOUTH IN THE BOOK ARE ACTUAL QUOTES FROM REAL KIDS WHO ARE LIVING IN FAMILIES IMPACTED WITH ALS – JUST LIKE YOU.

WE LIKE GRAPHIC NOVELS AND HOPE YOU WILL TOO. IT CAN MAKE TALKING ABOUT ALS A LOT EASIER. THANK YOU TO ALL THE FAMILIES WHO PARTICIPATED IN THE NATIONAL ALS FAMILY AND YOUTH STUDY, AND TO BELLA – WHO SHARED HER STORY AND HER ART TO MAKE THIS BOOK HAPPEN.



CHAPTER 1:
WHAT IS ALS?



IT ATTACKS THE MUSCLES AND DESTROYS THEM.

YES, ALISON, THAT IS CORRECT!

ALS HAPPENS WHEN THE NEURONS STOP TALKING TO YOUR MUSCLES, LIKE WHEN THE PHONE CUTS OFF AND YOU CAN'T HEAR THE OTHER PERSON. WHEN THIS HAPPENS, SOMEONE WITH ALS CAN'T USE THEIR ARMS LIKE THEY USED TO BECAUSE THE MUSCLES DON'T KNOW WHAT TO DO.



MY DAD CAN'T MOVE.

YOU'RE RIGHT, CARRIE. MANY PEOPLE WITH ALS CAN'T MOVE. BUT NOT EVERYONE AND NOT RIGHT AWAY. THAT'S CONFUSING, ISN'T IT?

ALS LOOKS DIFFERENT IN DIFFERENT PEOPLE. ALL THE PEOPLE IN THESE PICTURES HAVE ALS.

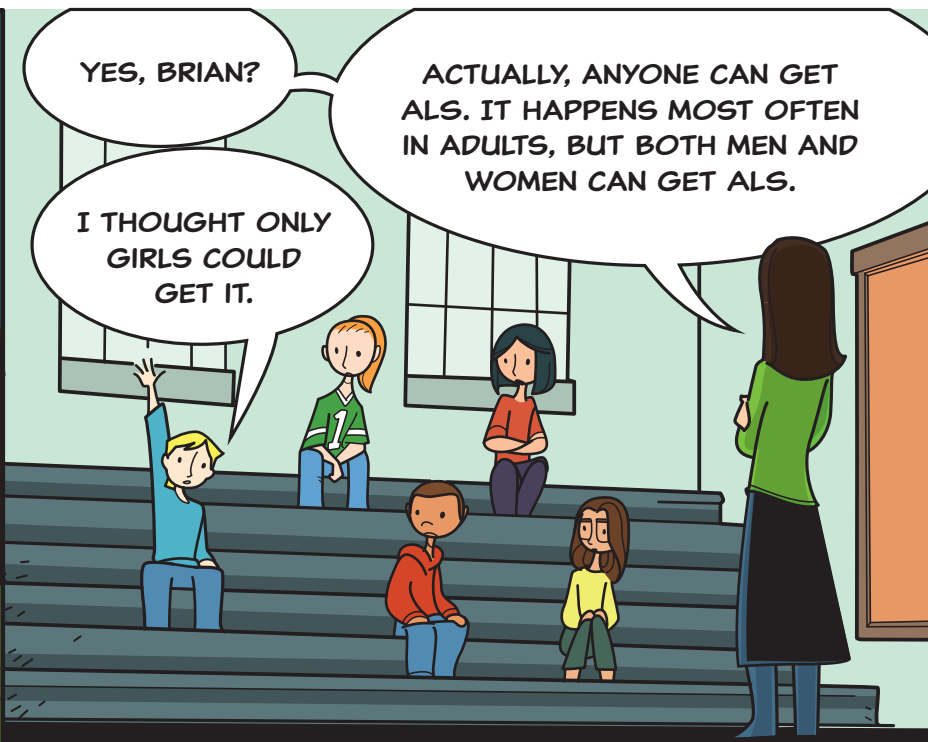
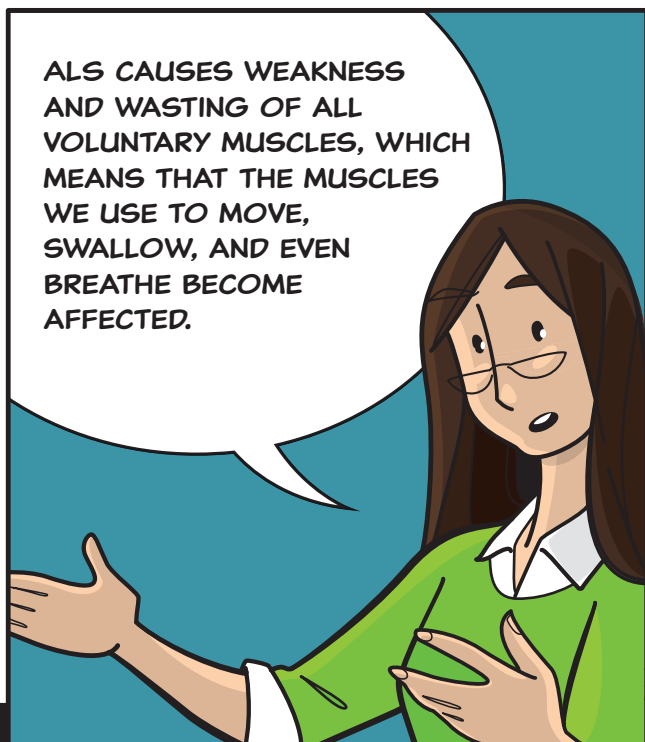
WHAT IS ALS

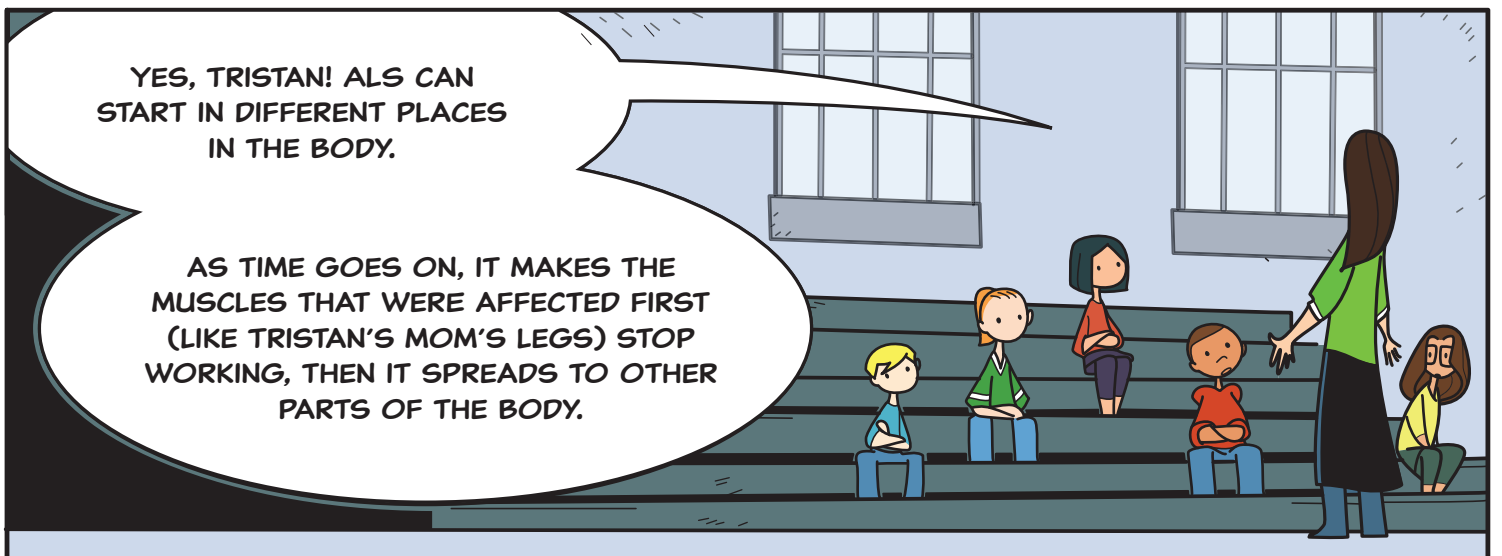
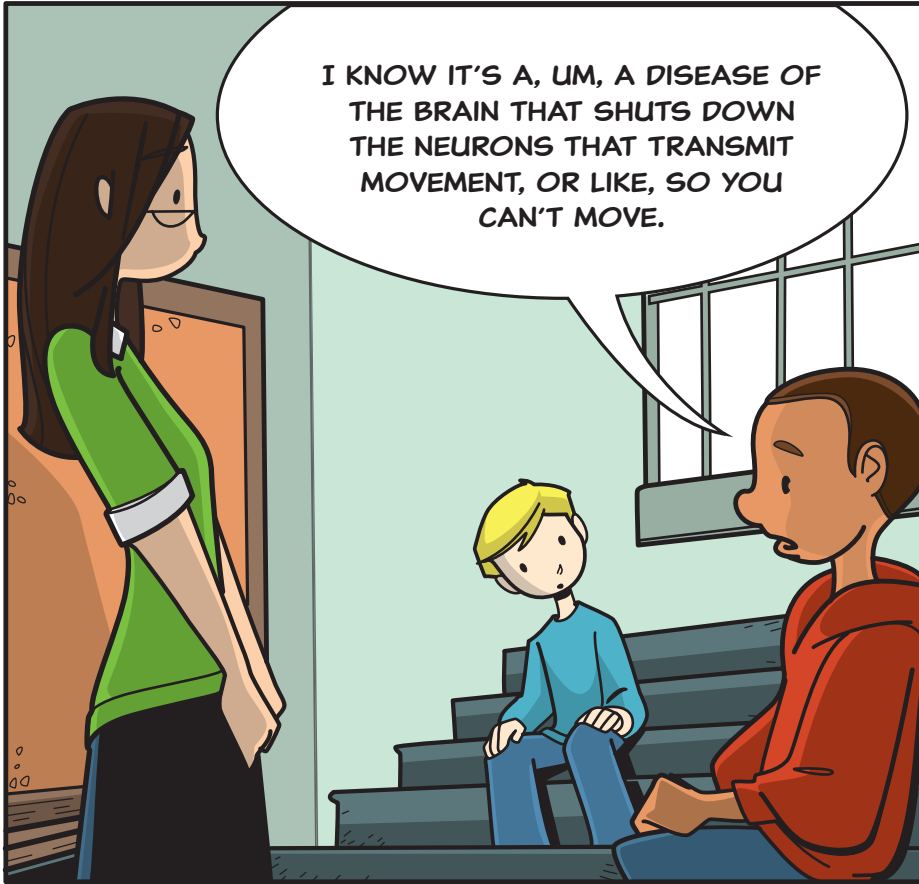
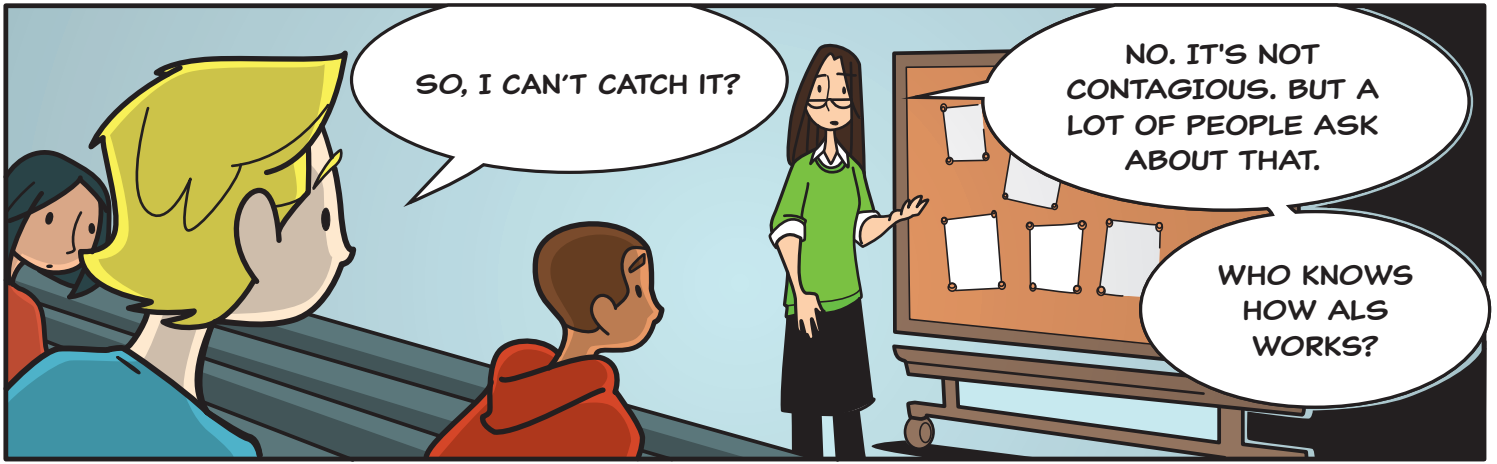
ALS CAUSES WEAKNESS AND WASTING OF ALL VOLUNTARY MUSCLES, WHICH MEANS THAT THE MUSCLES WE USE TO MOVE, SWALLOW, AND EVEN BREATHE BECOME AFFECTED.

YES, BRIAN?

I THOUGHT ONLY GIRLS COULD GET IT.

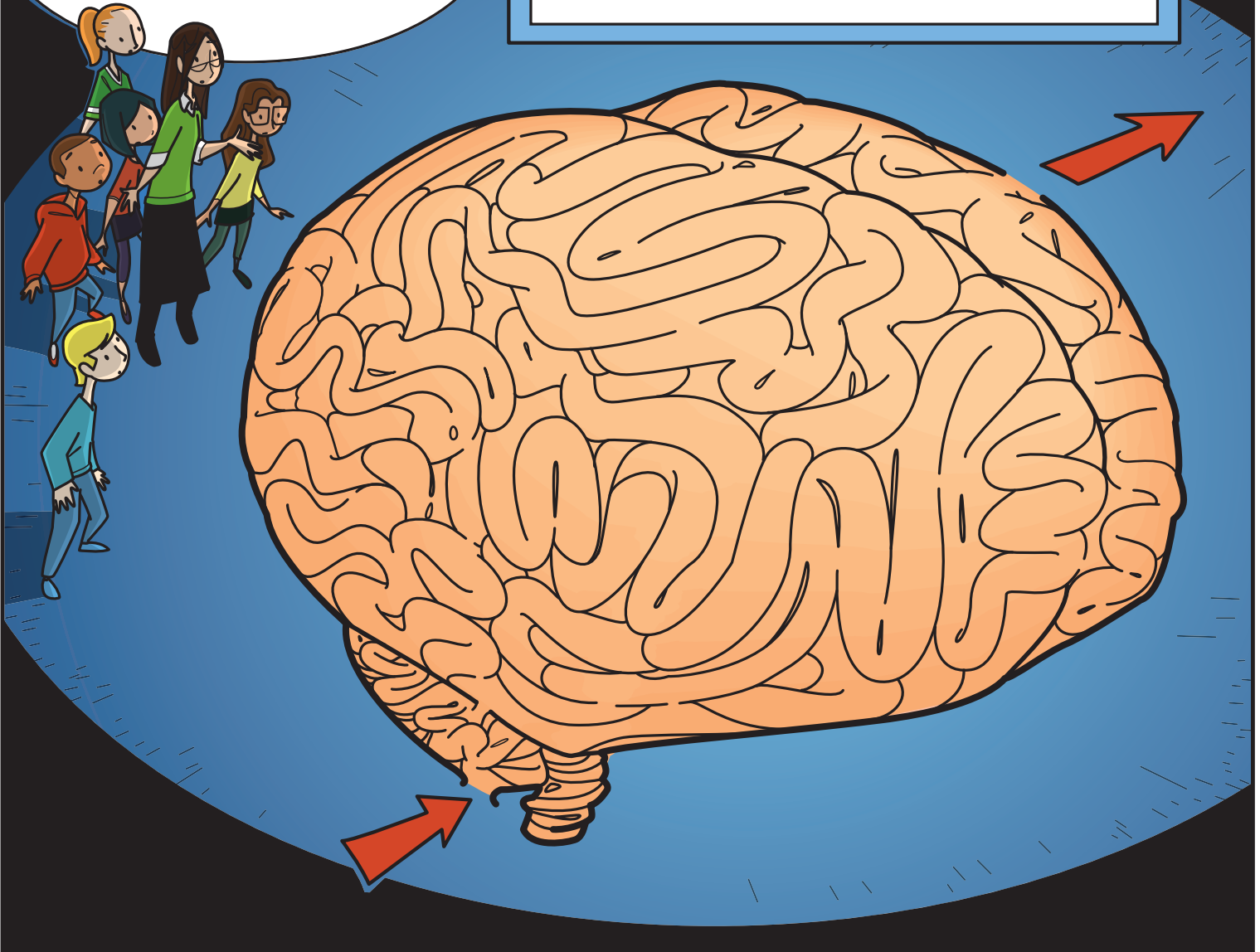
ACTUALLY, ANYONE CAN GET ALS. IT HAPPENS MOST OFTEN IN ADULTS, BUT BOTH MEN AND WOMEN CAN GET ALS.





BRAINS ARE VERY COOL THINGS. THEY ARE THE CONTROL CENTER FOR HOW WE TALK, WALK, AND THINK.

USE THIS MAZE TO WALK THROUGH THE BRAIN. SEE IF YOU CAN MAKE IT ALL THE WAY THOUGH!



SO, BRAINS, ALS, NEURONS - LOTS OF IMPORTANT TOPICS. DOES ANYONE HAVE ANY QUESTIONS?

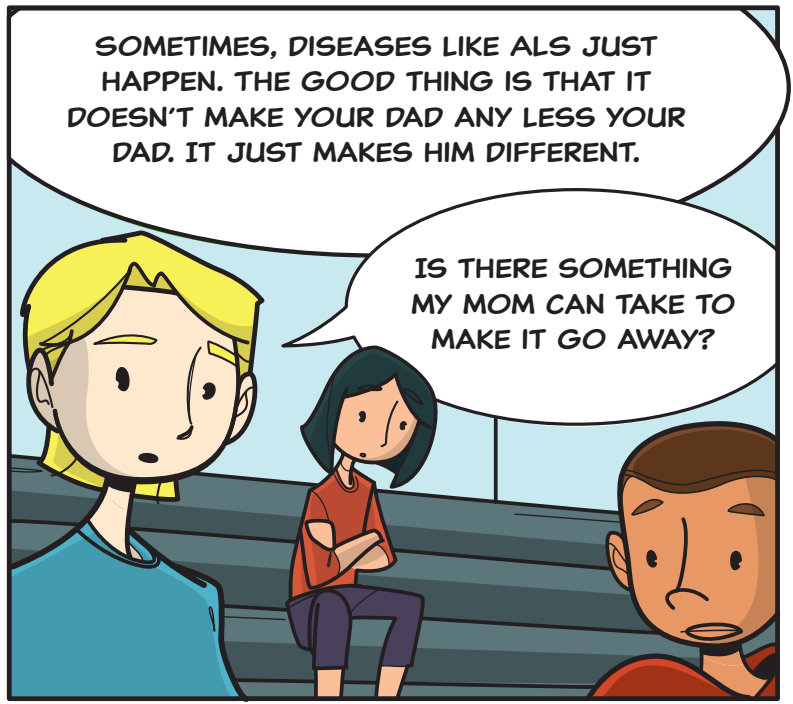




WHY DID MY DAD GET ALS?

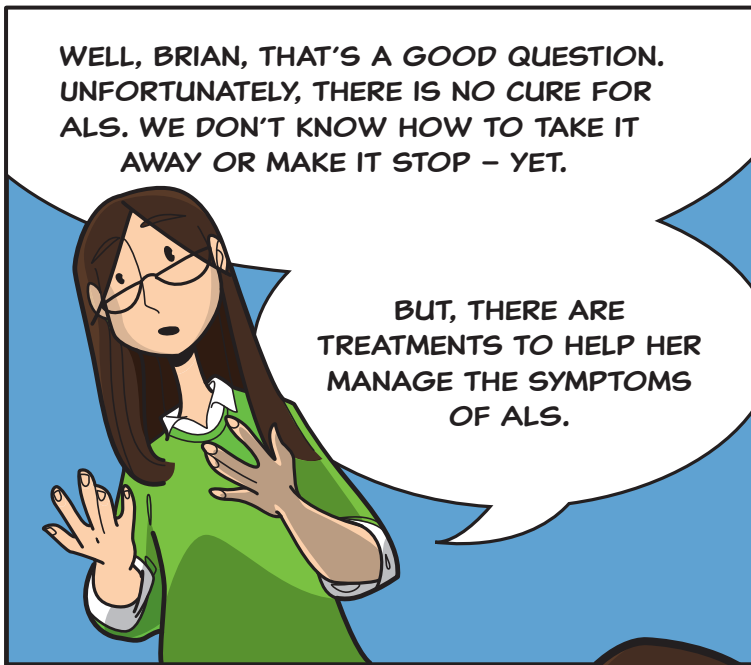
YES.

WE DON'T KNOW, ALISON. THAT'S HARD TO HEAR ISN'T IT?



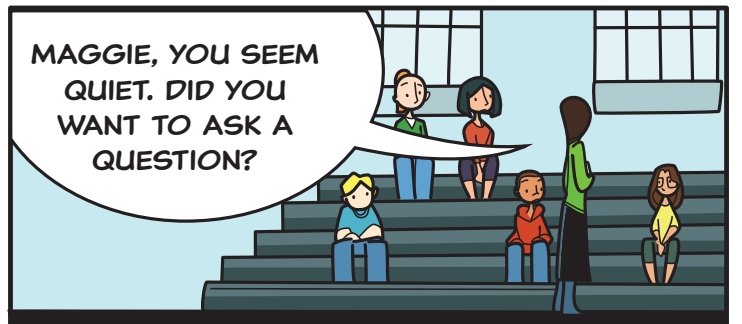
SOMETIMES, DISEASES LIKE ALS JUST HAPPEN. THE GOOD THING IS THAT IT DOESN'T MAKE YOUR DAD ANY LESS YOUR DAD. IT JUST MAKES HIM DIFFERENT.

IS THERE SOMETHING MY MOM CAN TAKE TO MAKE IT GO AWAY?



WELL, BRIAN, THAT'S A GOOD QUESTION. UNFORTUNATELY, THERE IS NO CURE FOR ALS. WE DON'T KNOW HOW TO TAKE IT AWAY OR MAKE IT STOP - YET.

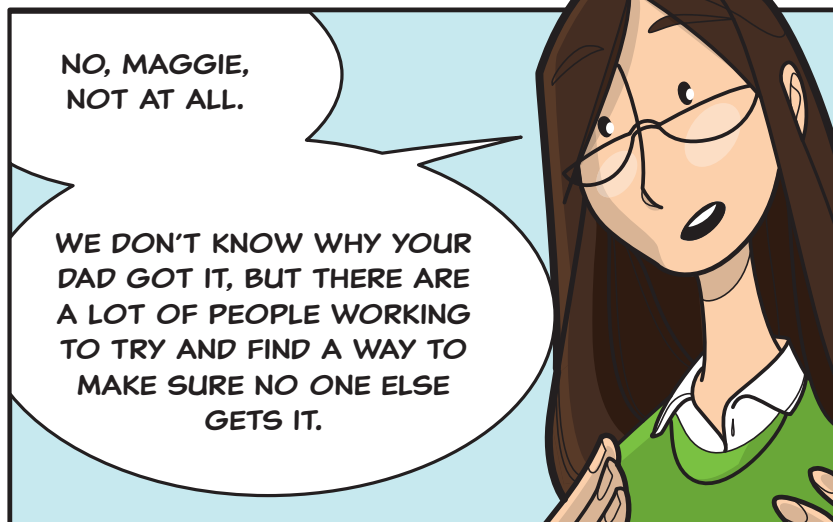
BUT, THERE ARE TREATMENTS TO HELP HER MANAGE THE SYMPTOMS OF ALS.



MAGGIE, YOU SEEM QUIET. DID YOU WANT TO ASK A QUESTION?



DID I DO SOMETHING TO MAKE HIM GET ALS?

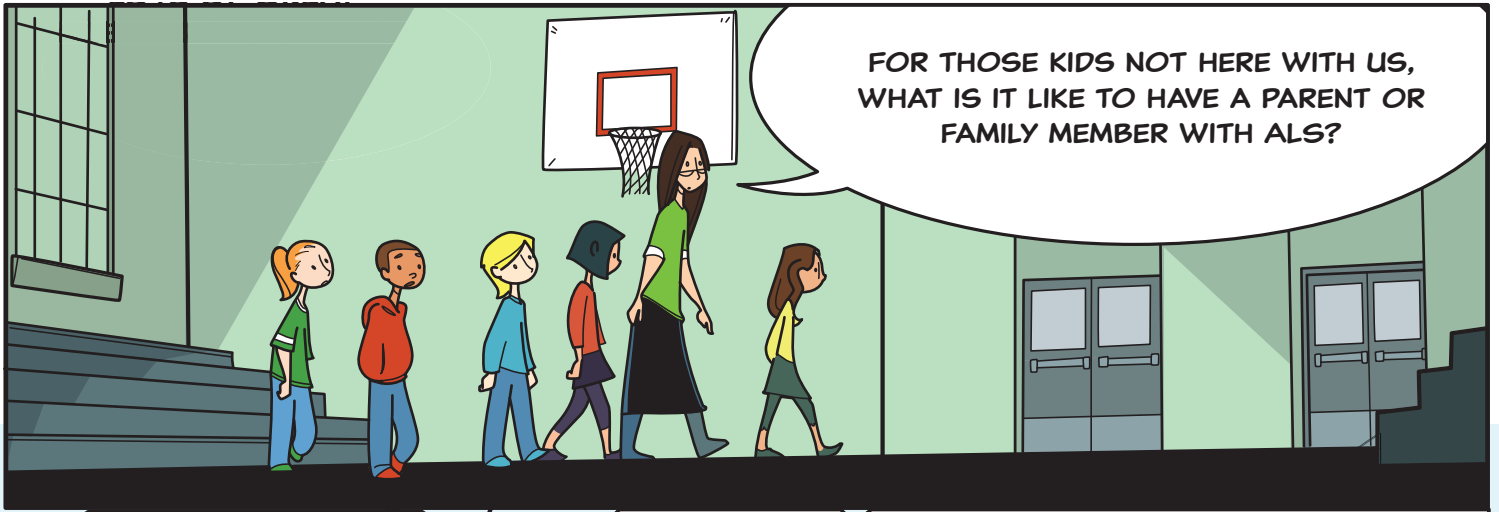


NO, MAGGIE, NOT AT ALL.

WE DON'T KNOW WHY YOUR DAD GOT IT, BUT THERE ARE A LOT OF PEOPLE WORKING TO TRY AND FIND A WAY TO MAKE SURE NO ONE ELSE GETS IT.



LIKE THESE SCIENTISTS!



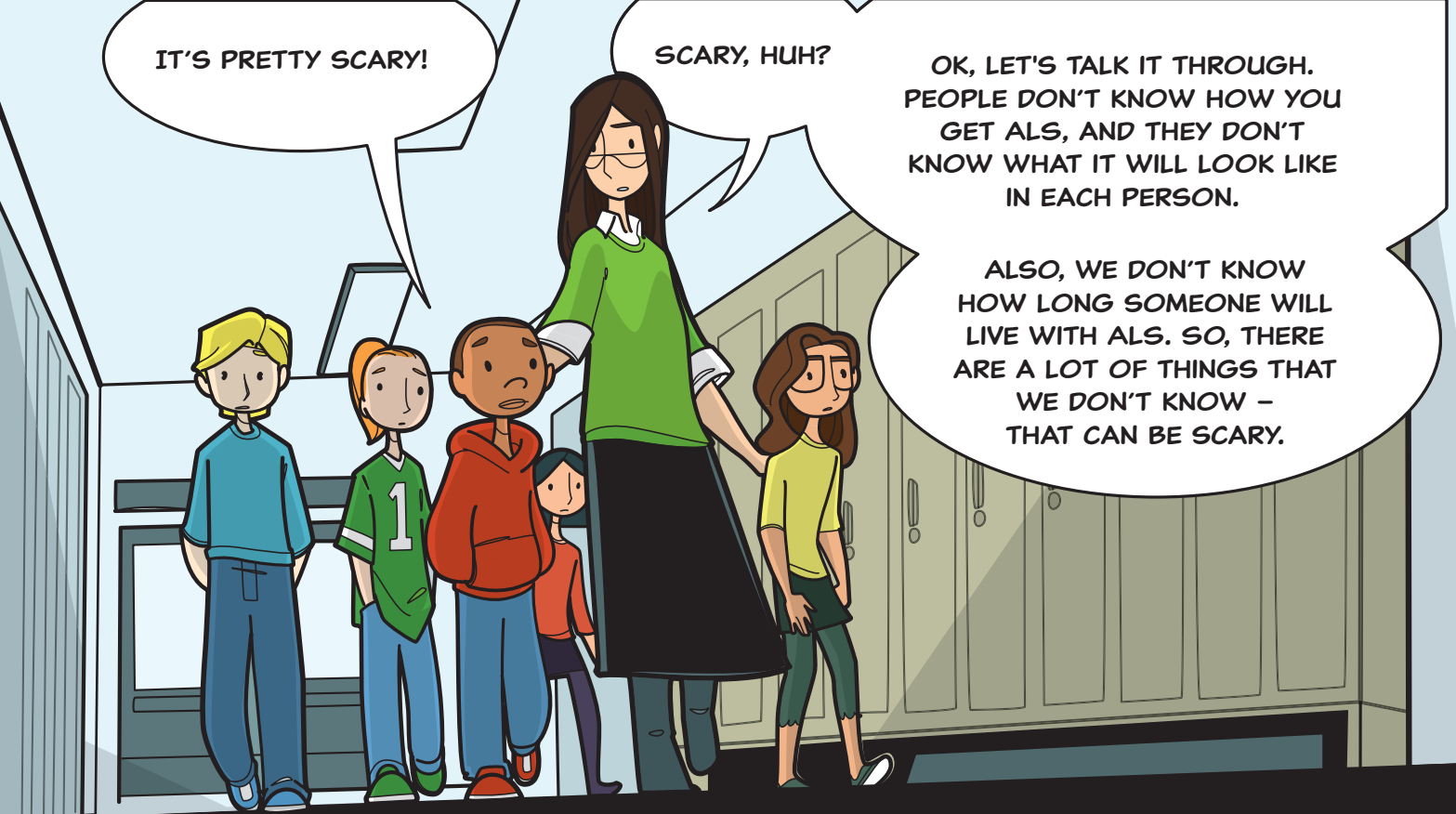
FOR THOSE KIDS NOT HERE WITH US, WHAT IS IT LIKE TO HAVE A PARENT OR FAMILY MEMBER WITH ALS?

IT'S PRETTY SCARY!

SCARY, HUH?

OK, LET'S TALK IT THROUGH. PEOPLE DON'T KNOW HOW YOU GET ALS, AND THEY DON'T KNOW WHAT IT WILL LOOK LIKE IN EACH PERSON.

ALSO, WE DON'T KNOW HOW LONG SOMEONE WILL LIVE WITH ALS. SO, THERE ARE A LOT OF THINGS THAT WE DON'T KNOW - THAT CAN BE SCARY.



YOU'RE NOT ALONE. YOUNG PEOPLE TALK A LOT ABOUT BEING WORRIED AND NOT KNOWING WHO TO TALK TO. WHEN WE TALK AND SHARE OUR FEARS, WE HELP EACH OTHER FEEL BETTER.

I WANT TO TELL YOU ABOUT BELLA.



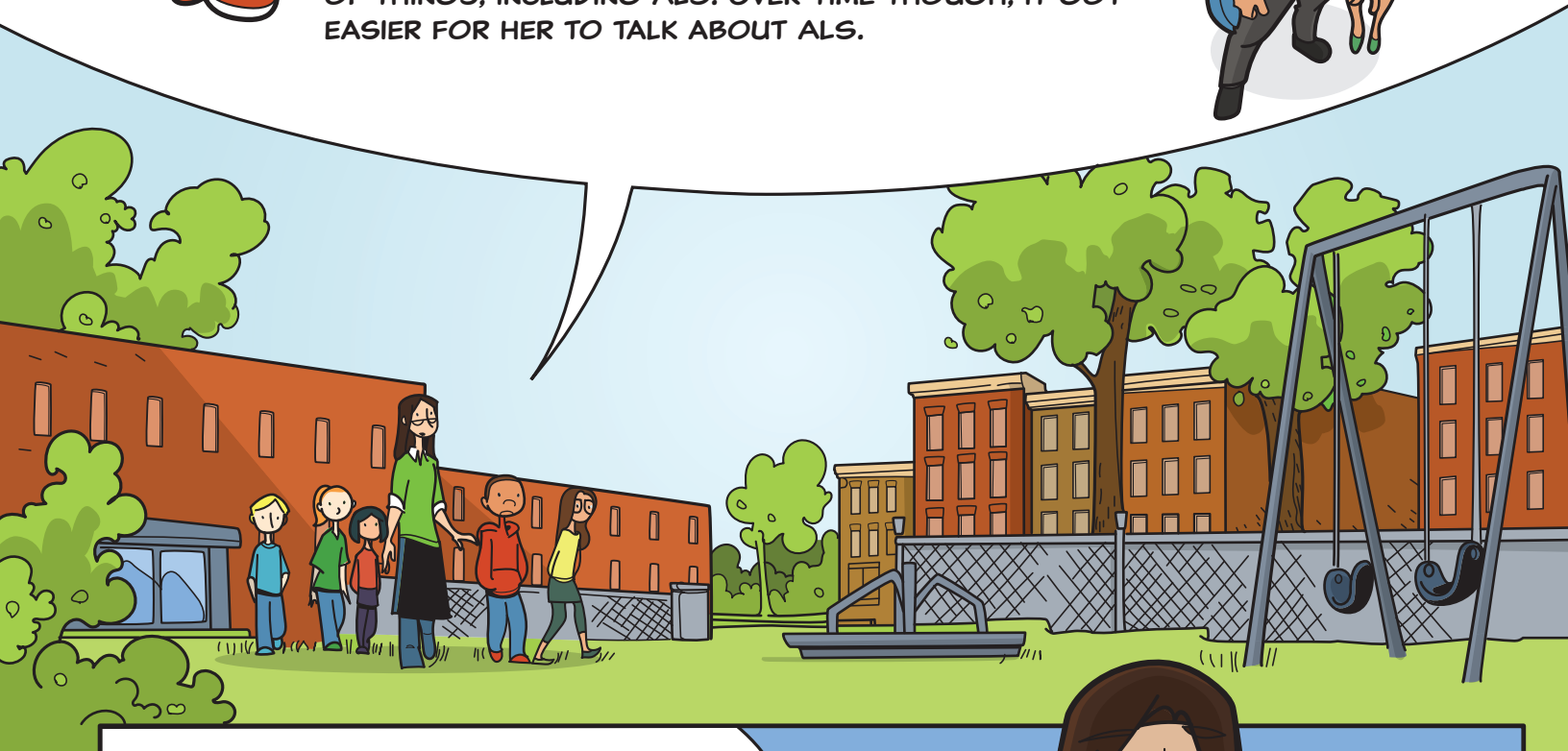
CHAPTER 2: TALKING ABOUT ALS



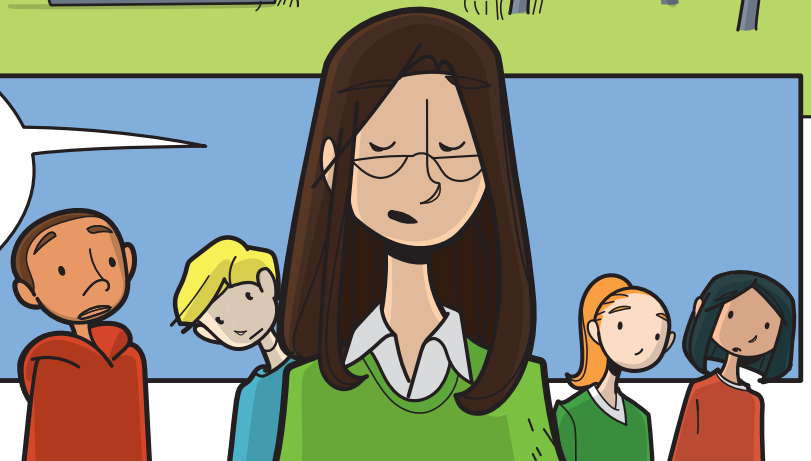
BELLA IS 11 YEARS OLD. HER DAD HAD ALS. I SAY HAD, BECAUSE HE DIED JUST THIS YEAR. HER DAD DID NOT HAVE ALS FOR VERY LONG, SO IT WAS REALLY HARD TO UNDERSTAND WHAT WAS HAPPENING.

BELLA KNEW SOMETHING WAS GOING ON WHEN HER DAD WOULD FALL—A LOT. THEN HIS VOICE STARTED TO SOUND FUNNY. BELLA WAS REALLY CLOSE TO HER DAD, HE WOULD OFTEN TEASE HER AND JOKE AROUND WITH HER, SO SHE STARTED TO GET SCARED THAT SOMETHING REALLY BAD WAS HAPPENING.

HER FAMILY DID NOT TALK TOO MUCH ABOUT WHAT WAS HAPPENING, BECAUSE THEY DID NOT WANT TO WORRY BELLA. THEY WENT TO A LOT OF DOCTORS, AND FINALLY GOT ONE WHO DIAGNOSED HER DAD WITH ALS. BELLA SAYS GETTING THE DIAGNOSIS WAS DIFFICULT FOR HER BECAUSE SHE GETS ANXIOUS AND IS SOMETIMES AFRAID OF TALKING TO FAMILY MEMBERS ABOUT A LOT OF THINGS, INCLUDING ALS. OVER TIME THOUGH, IT GOT EASIER FOR HER TO TALK ABOUT ALS.

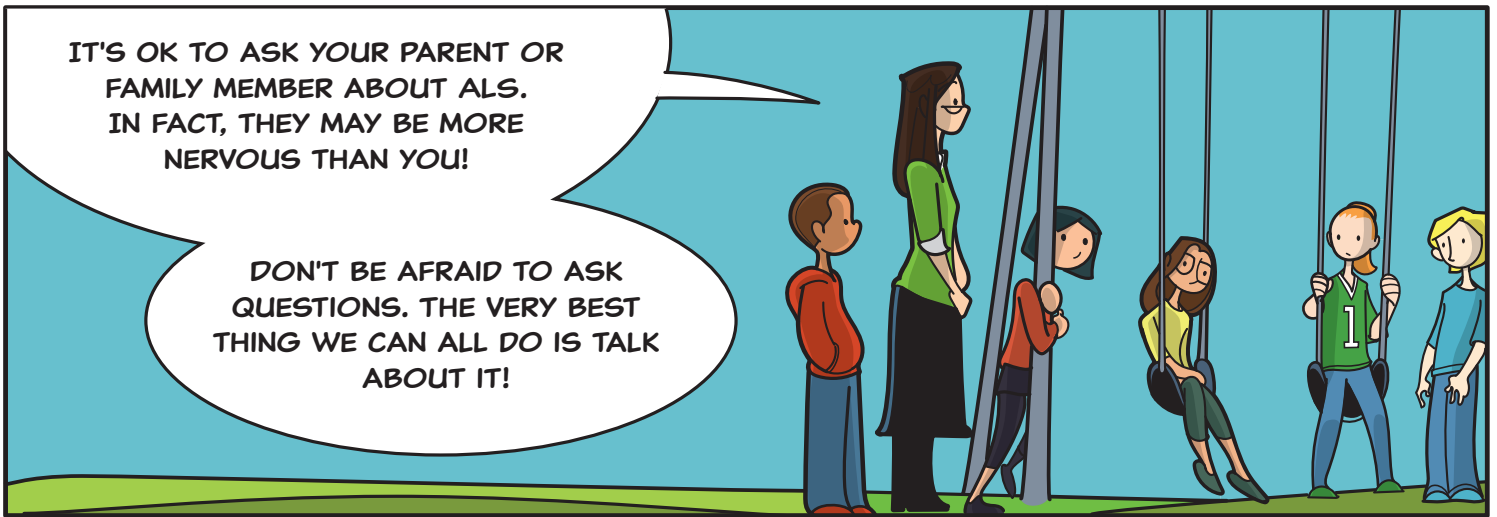


BELLA'S EXPERIENCE IS REALLY COMMON. SOMETIMES FAMILIES DON'T TALK BECAUSE THEY DON'T WANT TO UPSET EACH OTHER. BUT, LIKE BELLA, YOU PROBABLY HAVE LOTS OF QUESTIONS.



IT'S OK TO ASK YOUR PARENT OR FAMILY MEMBER ABOUT ALS. IN FACT, THEY MAY BE MORE NERVOUS THAN YOU!

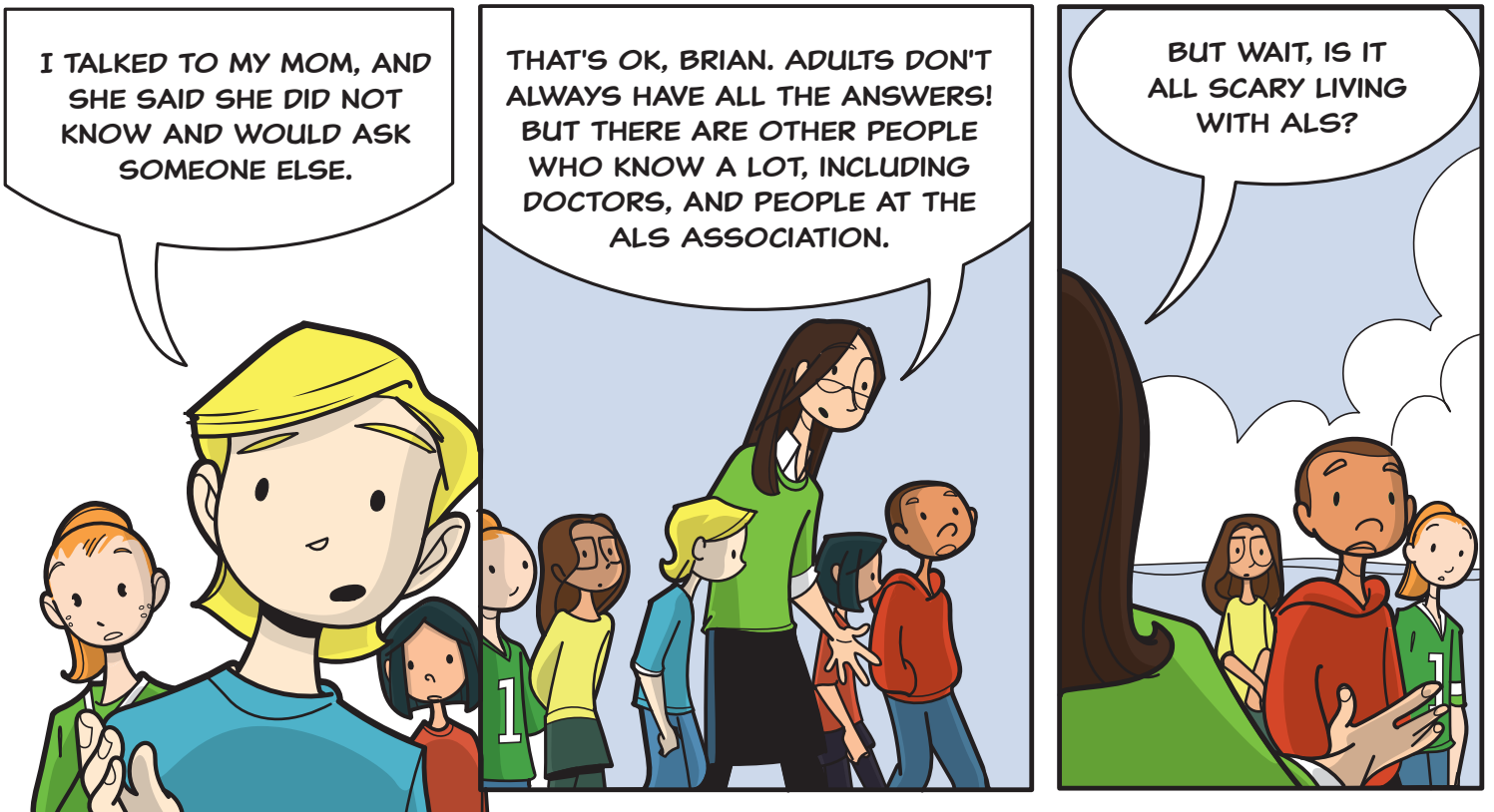
DON'T BE AFRAID TO ASK QUESTIONS. THE VERY BEST THING WE CAN ALL DO IS TALK ABOUT IT!



I TALKED TO MY MOM, AND SHE SAID SHE DID NOT KNOW AND WOULD ASK SOMEONE ELSE.

THAT'S OK, BRIAN. ADULTS DON'T ALWAYS HAVE ALL THE ANSWERS! BUT THERE ARE OTHER PEOPLE WHO KNOW A LOT, INCLUDING DOCTORS, AND PEOPLE AT THE ALS ASSOCIATION.

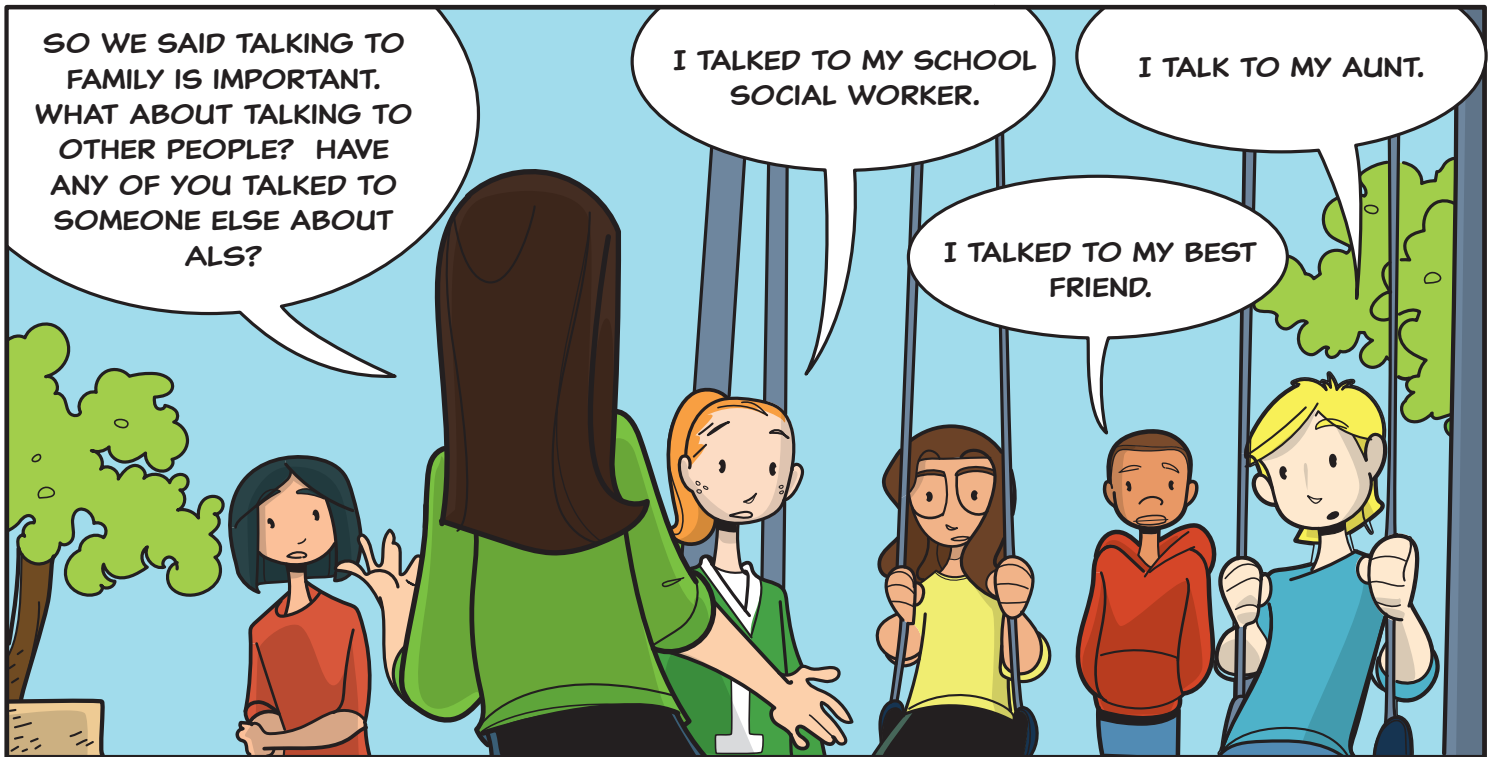
BUT WAIT, IS IT ALL SCARY LIVING WITH ALS?



IT'S NOT THAT DIFFERENT FROM LIVING WITH SOMEONE WITHOUT IT. IT'S THE SAME PERSON, AND IT'S REALLY JUST A PHYSICAL DISEASE THAT'S AFFECTING THEM. THERE'S CERTAIN RESPONSIBILITIES THAT YOU NEED TO TAKE ON, BUT IT'S WORTH IT BECAUSE YOU LOVE THAT PERSON.

GREAT ANSWER, TRISTAN!



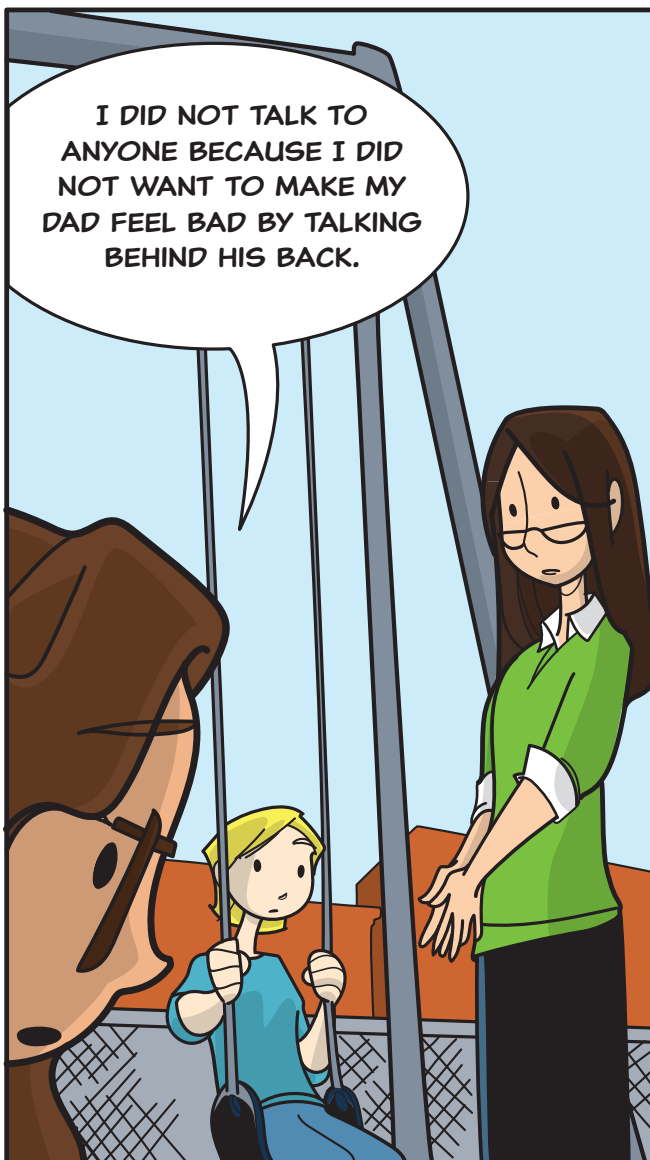


SO WE SAID TALKING TO FAMILY IS IMPORTANT. WHAT ABOUT TALKING TO OTHER PEOPLE? HAVE ANY OF YOU TALKED TO SOMEONE ELSE ABOUT ALS?

I TALKED TO MY SCHOOL SOCIAL WORKER.

I TALK TO MY AUNT.

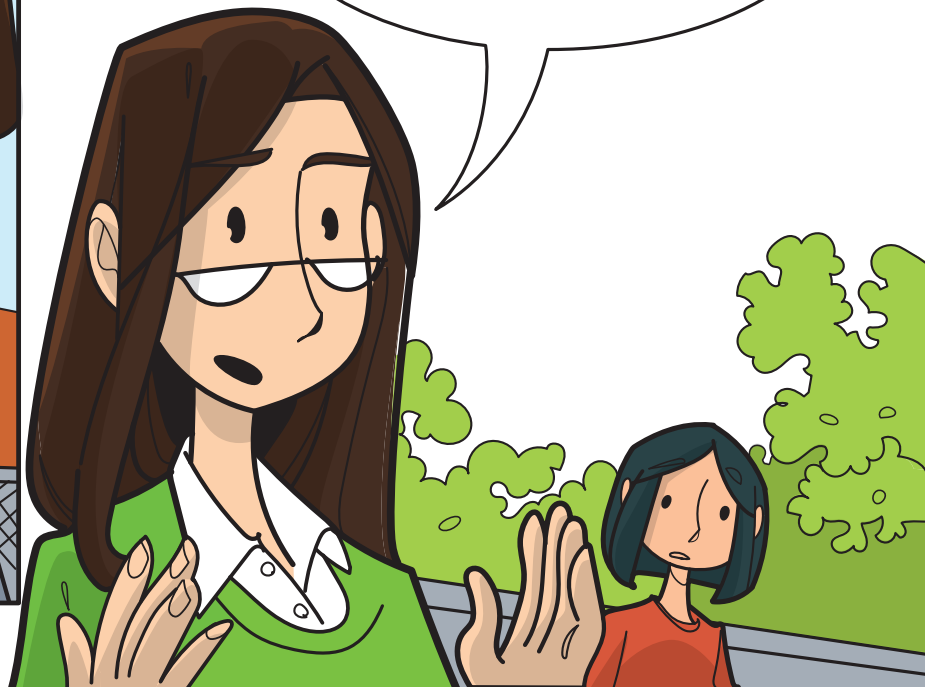
I TALKED TO MY BEST FRIEND.



I DID NOT TALK TO ANYONE BECAUSE I DID NOT WANT TO MAKE MY DAD FEEL BAD BY TALKING BEHIND HIS BACK.

THAT'S A GOOD POINT, MAGGIE. IT SHOWS HOW MUCH YOU LOVE YOUR DAD. IT MAKES SENSE THAT YOU DON'T WANT TO HURT HIM. BUT NEEDING TO SHARE YOUR FEELINGS WITH SOMEONE WON'T HURT HIM. YOU DESERVE TO TALK ABOUT YOUR FEELINGS WITH SOMEONE YOU TRUST. HOWEVER, WHAT YOU TALK ABOUT IS IMPORTANT.

IT'S OK FOR YOU TO BE SAD ABOUT HOW THINGS ARE CHANGING AND TO TALK ABOUT HOW YOU FEEL.



AT THE SAME TIME, YOU MAY NOT WANT TO TALK ABOUT ALS - WITH ANYONE

AND THAT'S OK. WE ALL FEEL LIKE TALKING SOMETIMES AND NOT TALKING AT OTHER TIMES. BUT NOT TALKING MAY MAKE YOU FEEL MORE SAD AND ANXIOUS - AND WORRIED AND ALONE.

YOU DON'T HAVE TO TALK ALL THE TIME, JUST MAKE SURE YOU TALK SOME OF THE TIME.

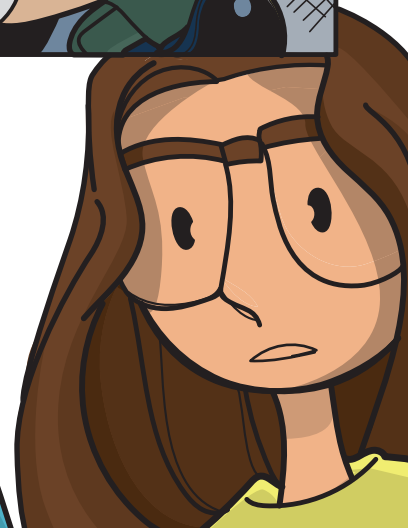
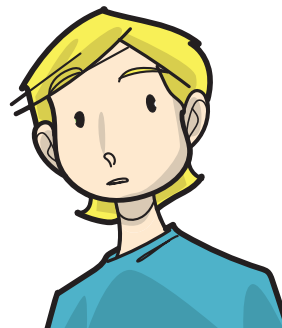
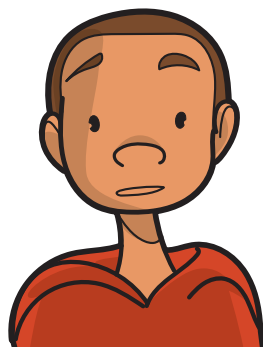
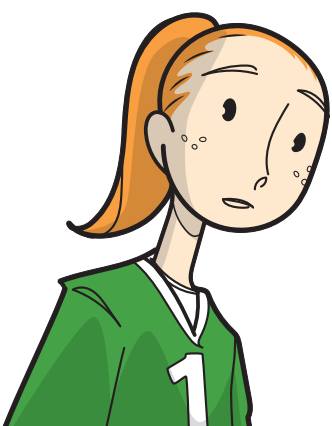
OK, NOW LET'S TALK ABOUT....

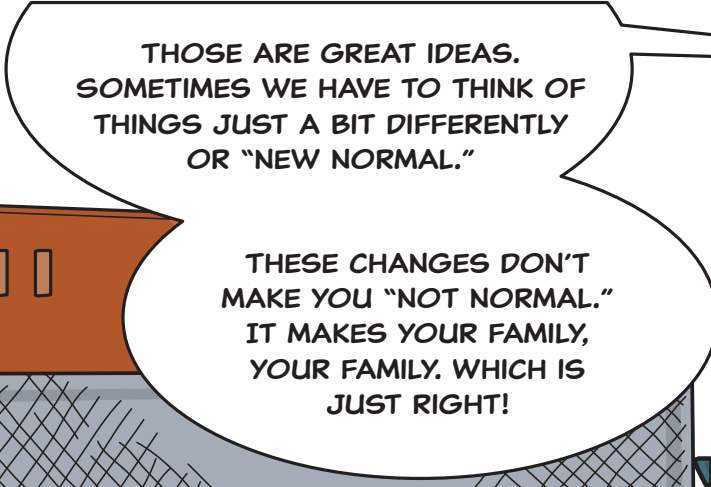
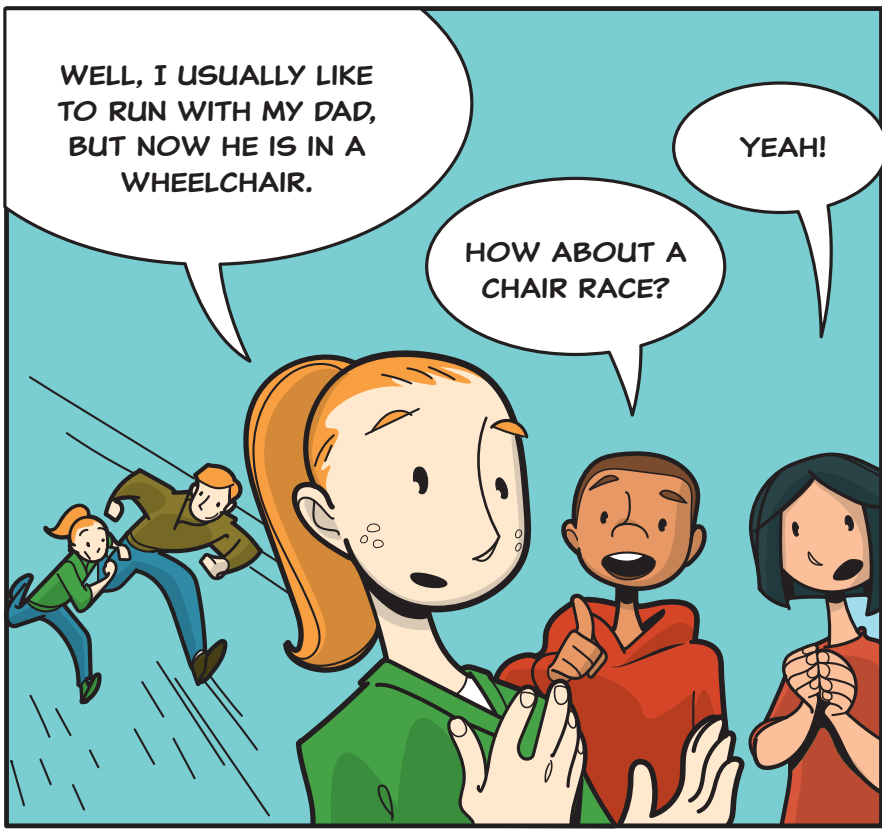
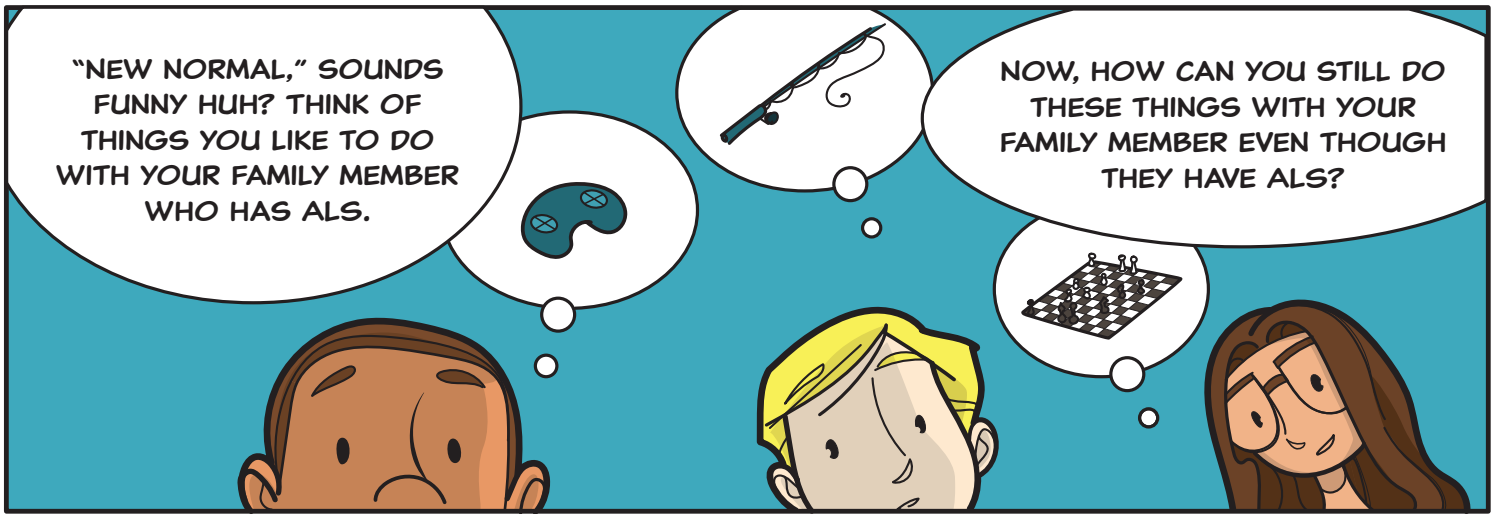
YASMINE, DID YOU HAVE A QUESTION?

WELL, NOT REALLY A QUESTION, BUT BECAUSE MY DAD HAS ALS, I DON'T FEEL LIKE A NORMAL FAMILY ANYMORE.

THANK YOU, YASMINE, FOR SHARING THAT. LOTS OF KIDS FEEL THE SAME WAY. THE TRUTH IS, THINGS ARE DIFFERENT, BUT STILL NORMAL -

JUST A "NEW NORMAL."





THAT ACTUALLY TAKES US TO THE NEXT TOPIC -

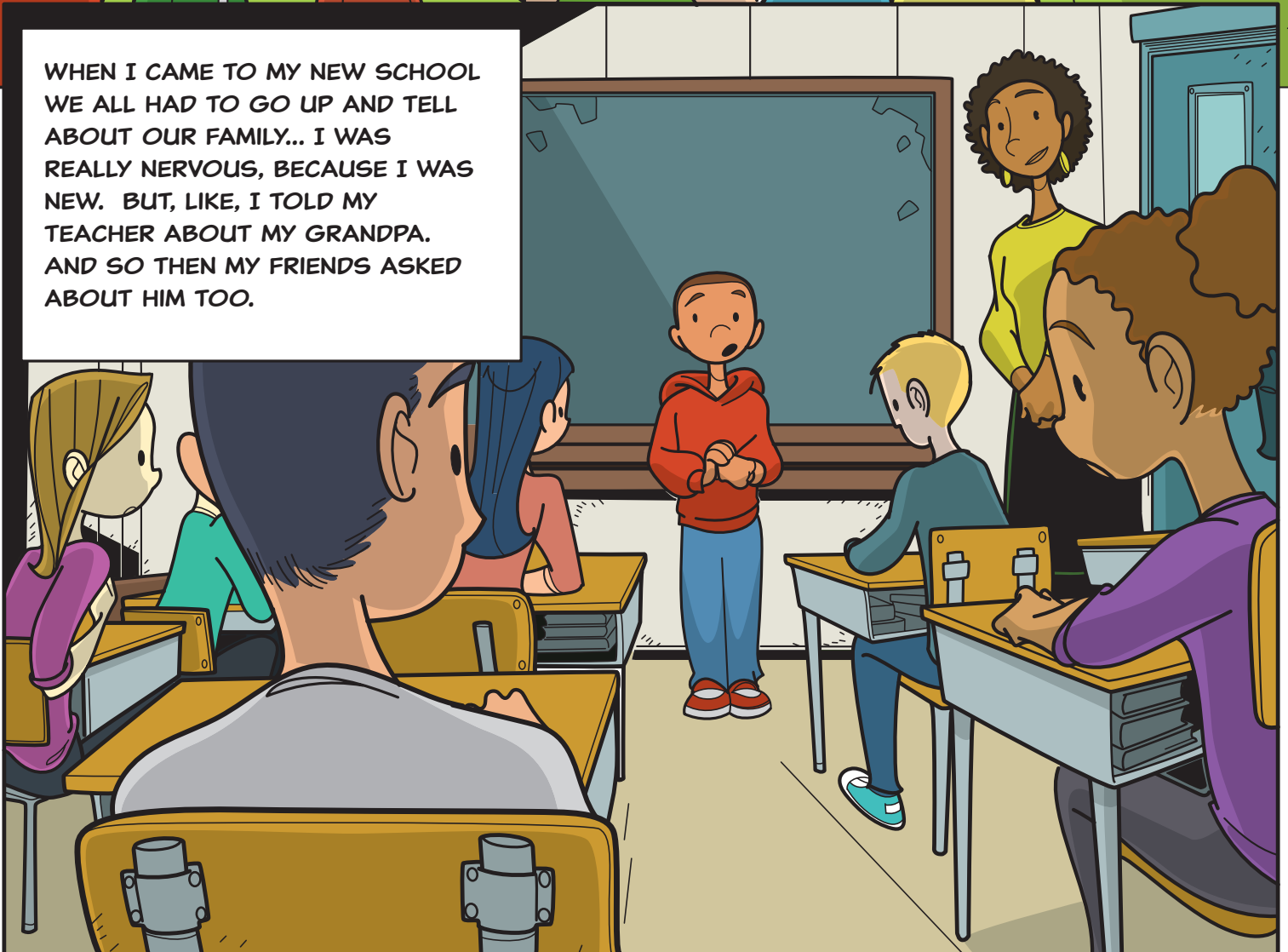
CHAPTER 3:
FRIENDS & SCHOOL

GOING BACK TO SCHOOL OR STARTING A NEW SCHOOL IS EXCITING, SCARY, AND CONFUSING. YOU GET TO MEET NEW FRIENDS FOR THE FIRST TIME OR SEE OLD FRIENDS.

IT'S NORMAL TO LOOK AT THE OTHER STUDENTS AND WONDER WHAT THEY ARE LIKE. WHAT IS THEIR FAMILY LIKE? ESPECIALLY IF ALS IS A NEW DIAGNOSIS IN YOUR FAMILY.

TRISTAN, I KNOW YOU STARTED AT A NEW SCHOOL. WHAT WAS THAT LIKE?

WHEN I CAME TO MY NEW SCHOOL WE ALL HAD TO GO UP AND TELL ABOUT OUR FAMILY... I WAS REALLY NERVOUS, BECAUSE I WAS NEW. BUT, LIKE, I TOLD MY TEACHER ABOUT MY GRANDPA. AND SO THEN MY FRIENDS ASKED ABOUT HIM TOO.



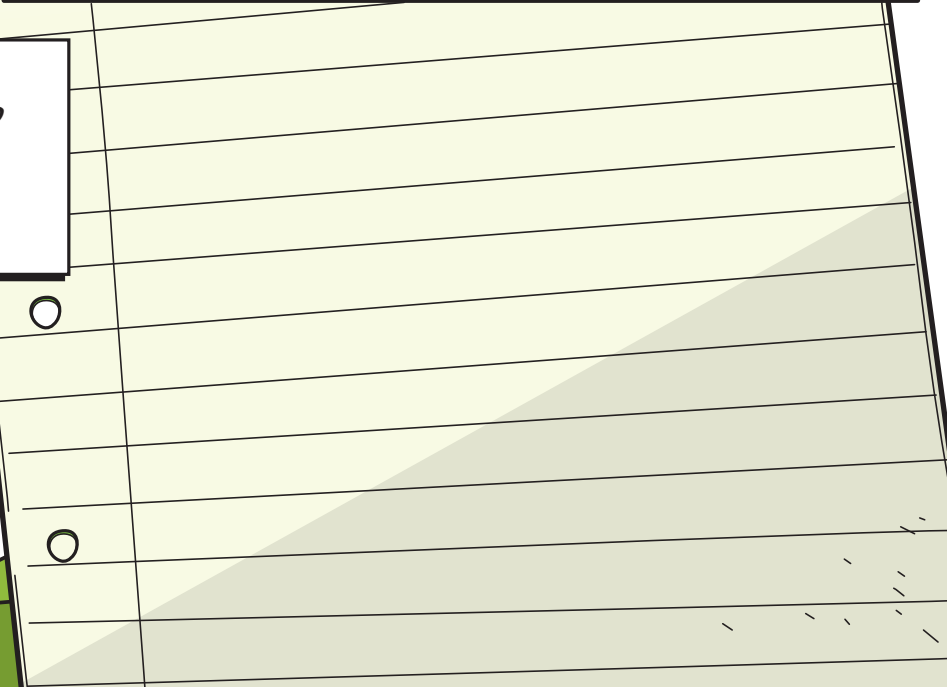
WHAT WAS REALLY COOL ABOUT TRISTAN WAS THAT HE HAD A CHANCE TO TELL HIS NEW CLASSMATES ABOUT ALS AND HIS GRANDPA. NOT EVERYONE WILL FEEL COMFORTABLE DOING THIS, SO IF YOU DON'T FEEL READY, THAT'S FINE.


YES, ALISON?

AT MY OLD SCHOOL, THEY ALWAYS ASKED HOW MY DAD WAS DOING. AND, LIKE, MY TEACHERS SOMETIMES STILL ASK ME IF MY DAD FEELS GOOD. AND, LIKE, MY PRINCIPAL DOES, TOO.

THAT'S GREAT ALISON. SHARING WITH THE SCHOOL IS IMPORTANT. HERE ARE SOME WAYS YOU AND YOUR PARENTS CAN THINK ABOUT TALKING TO YOUR SCHOOL.

DO YOU FEEL COMFORTABLE TALKING TO YOUR TEACHER? WOULD YOU PREFER A GROUP MEETING, OR WOULD YOU LIKE TO TALK TO THE TEACHER/COUNSELOR ALONE?





I WAS THE ONLY ONE IN MY CLASS WHOSE DAD WAS SICK, AND I COULDN'T REALLY GO ANYWHERE. BUT SOME OF MY FRIENDS UNDERSTOOD AND WERE REALLY NICE, AND THEY HELPED ME.



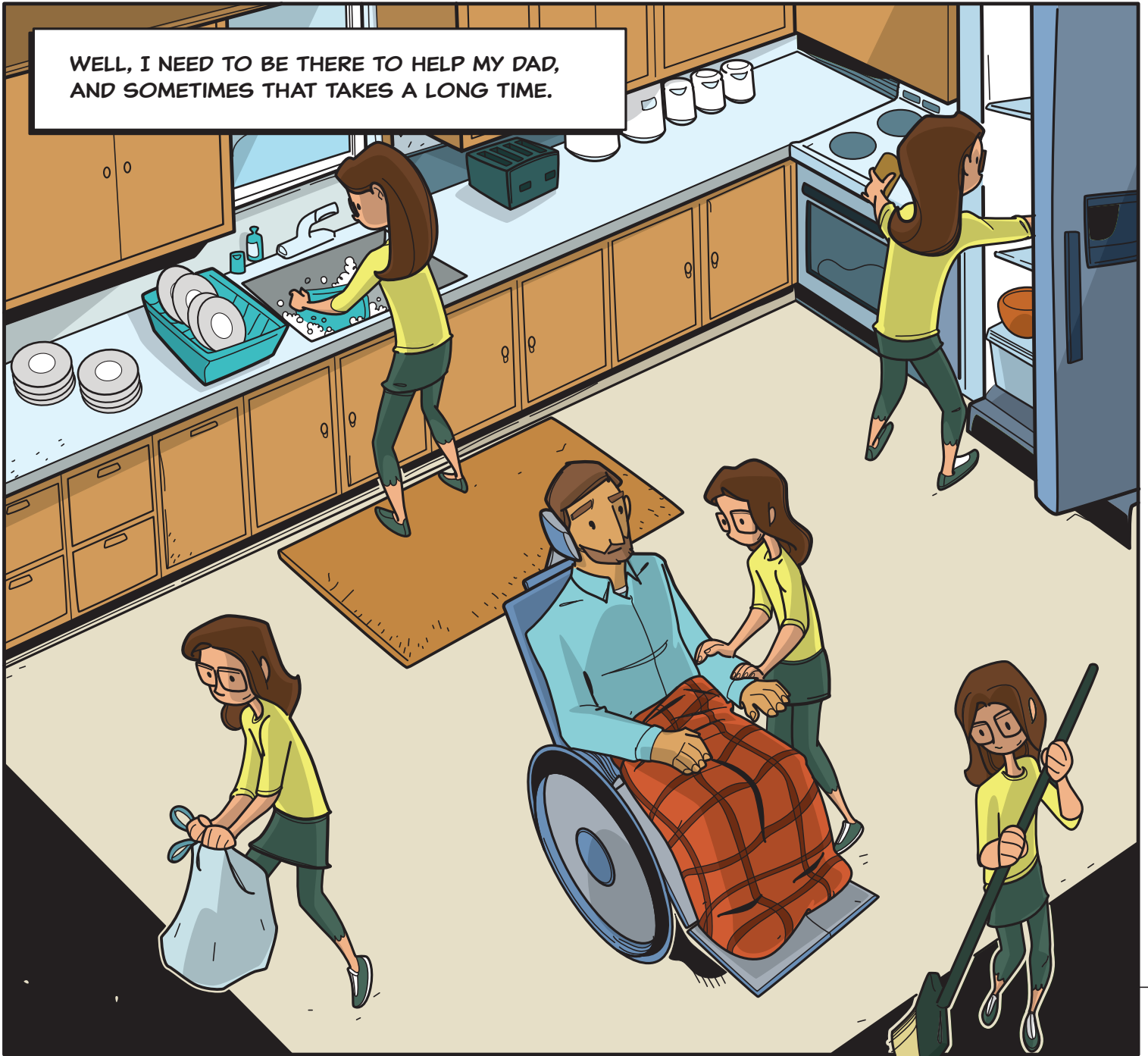
THANK YOU, YASMINE. TALKING TO OTHER KIDS ABOUT ALS CAN BE HARD – SPECIFICALLY WHEN THEY DON'T HAVE A FAMILY MEMBER WITH ALS. SO, WHEN YOU HAVE THE CHANCE, IT'S REALLY GOOD TO TALK ABOUT IT.



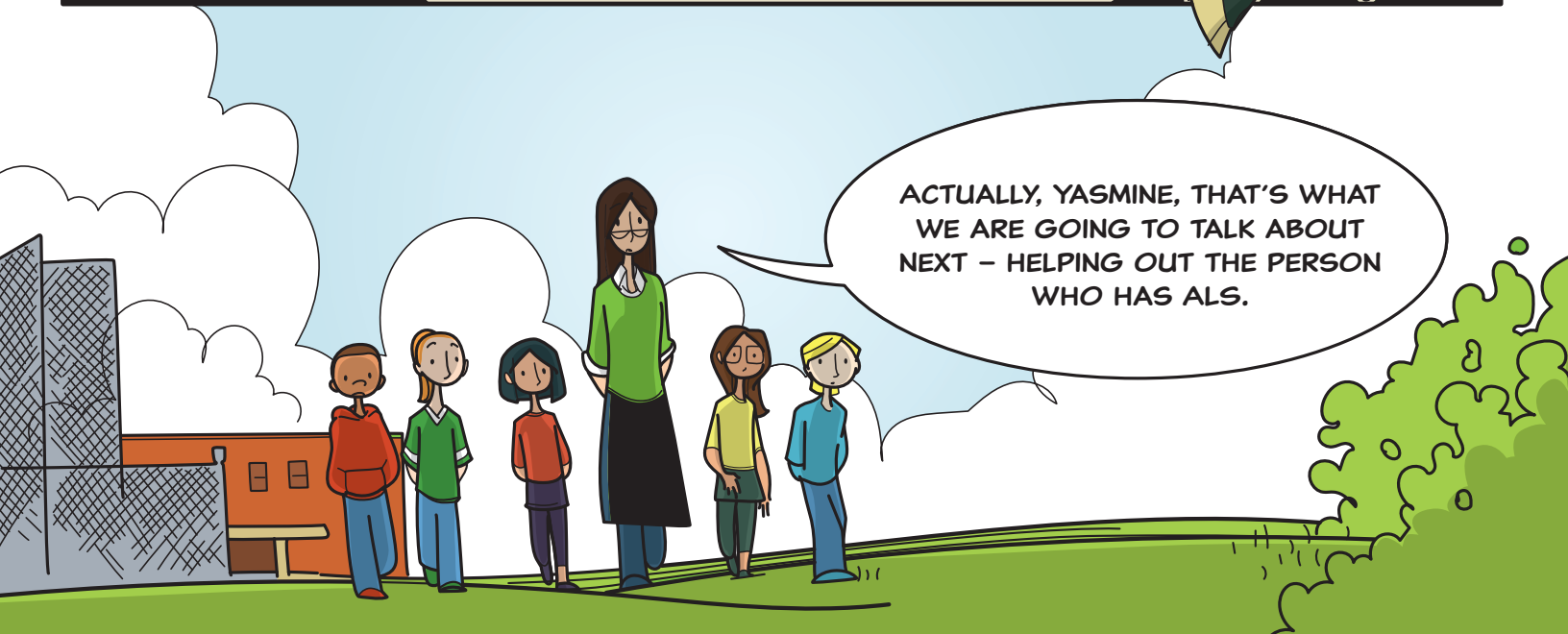
SPEAKING OF SCHOOL, HOW MANY OF YOU SOMETIMES DON'T GET YOUR HOMEWORK DONE BECAUSE YOU'RE HELPING OUT AROUND THE HOUSE, OR HELPING YOUR FAMILY MEMBER WITH ALS?



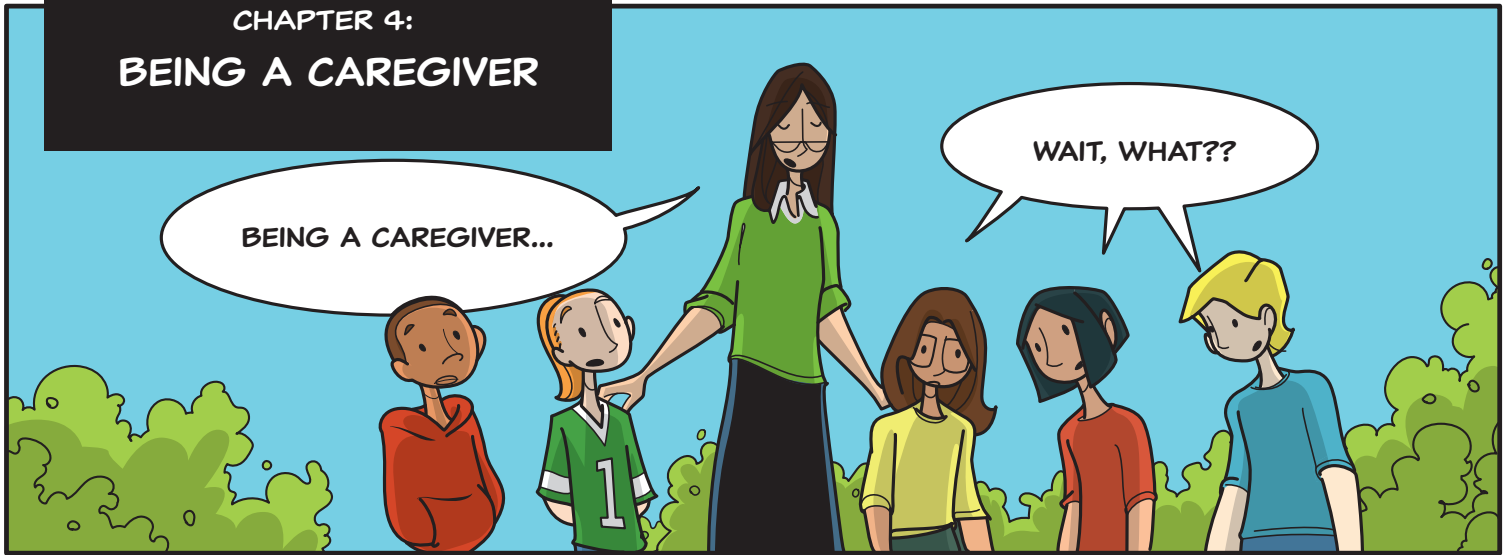
WELL, I NEED TO BE THERE TO HELP MY DAD,
AND SOMETIMES THAT TAKES A LONG TIME.



ACTUALLY, YASMINE, THAT'S WHAT
WE ARE GOING TO TALK ABOUT
NEXT - HELPING OUT THE PERSON
WHO HAS ALS.



CHAPTER 4:
BEING A CAREGIVER



BEING A CAREGIVER...

WAIT, WHAT??

OK, LET ME BACK UP.. TEACHERS AND RESEARCHERS USE THE TERM "CAREGIVER" TO DESCRIBE SOMEONE WHO DOES THINGS TO HELP, OR TAKE CARE OF, ANOTHER PERSON.

IN THIS CASE, IT'S KIDS LIKE YOU WHO HELP TAKE CARE OF A FAMILY MEMBER WITH ALS. IN FACT, WE ASKED KIDS IF THEY SAW THEMSELVES AS A CAREGIVER. MOST OF THEM DID, BUT SOME DID NOT.

NOT BECAUSE THEY WEREN'T PROVIDING CARE, BUT BECAUSE THEY JUST DIDN'T LIKE BEING CALLED A CAREGIVER. IT'S UP TO YOU!



WELL, I WOULD CALL MYSELF A CAREGIVER BECAUSE I DO MORE THAN A NORMAL KID WOULD DO FOR THEIR DAD. I HELP A LOT.

YOU'RE NOT ALONE, CARRIE. KIDS DO A LOT OF THINGS TO HELP OUT. WHO ELSE DOES THINGS TO TAKE CARE OF A FAMILY MEMBER WITH ALS?

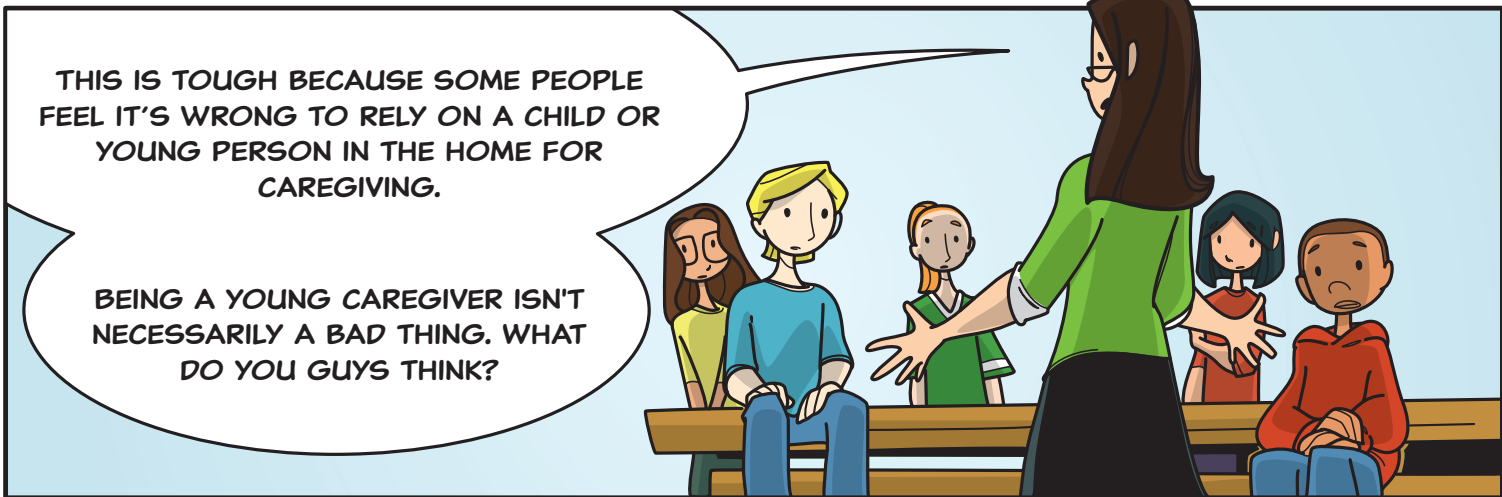
What is Caregiving?

SEE IF YOU CAN FIND SOME OF THE THINGS KIDS DO TO PROVIDE CARE.

WORD LIST

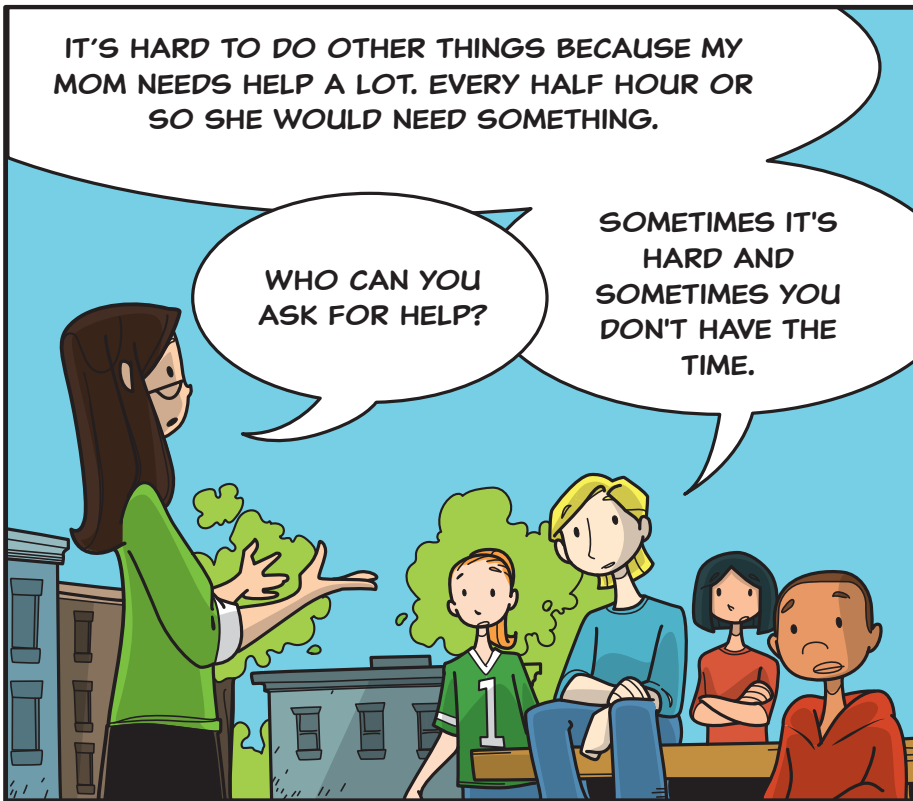
- BEING THERE
- DRESSING
- EXERCISES
- FEEDING
- HELP
- LISTEN
- LOVE
- SUPPORT
- THERAPY
- TIME

B L B V T C
 G T R S O K Q I H F
 U Z O N I R N S P W M T B J
 Y L W W V A I T L O V E L B S
 E U B E I N G T H E R E I E D
 G Z W D R E S S I N G S S Y G
 G N J S U P P O R T K M T T A
 A F E E D I N G U Y X E V
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THIS IS TOUGH BECAUSE SOME PEOPLE FEEL IT'S WRONG TO RELY ON A CHILD OR YOUNG PERSON IN THE HOME FOR CAREGIVING.

BEING A YOUNG CAREGIVER ISN'T NECESSARILY A BAD THING. WHAT DO YOU GUYS THINK?



IT'S HARD TO DO OTHER THINGS BECAUSE MY MOM NEEDS HELP A LOT. EVERY HALF HOUR OR SO SHE WOULD NEED SOMETHING.

WHO CAN YOU ASK FOR HELP?

SOMETIMES IT'S HARD AND SOMETIMES YOU DON'T HAVE THE TIME.



GRANDMA HELPS.

MY SISTER.

MY NEIGHBOR.

WE HAVE A CAREGIVER.



WHAT KINDS OF THINGS CAN PEOPLE DO TO HELP YOU?

HELP ME PUT HIM IN HIS WHEELCHAIR.

HELP ME KNOW WHAT TO DO AND HOW TO DO IT.

WOW! THOSE ARE ALL GREAT SUGGESTIONS! YES, KIDS LIKE YOU NEED A LOT OF SUPPORT AND HELP.

YES, BRIAN?

I DROPPED MY GRANDMA. I MEAN, NOT FAR, BUT I WAS TRYING TO MOVE HER, AND I DON'T THINK I DID IT RIGHT. SHE IS OK, BUT I FEEL BAD.

OF COURSE YOU FELT BAD, BRIAN! YOU'RE NOT THE ONLY ONE WHO HAS DONE SOMETHING LIKE THAT.

WHO ALWAYS KNOWS WHAT THEY ARE DOING?

BRIAN'S STORY SHOWS HOW IMPORTANT IT IS TO GET TRAINING AND HAVE PEOPLE TELL YOU HOW TO LIFT SOMEONE OR DO OTHER THINGS TO CARE FOR A PERSON.

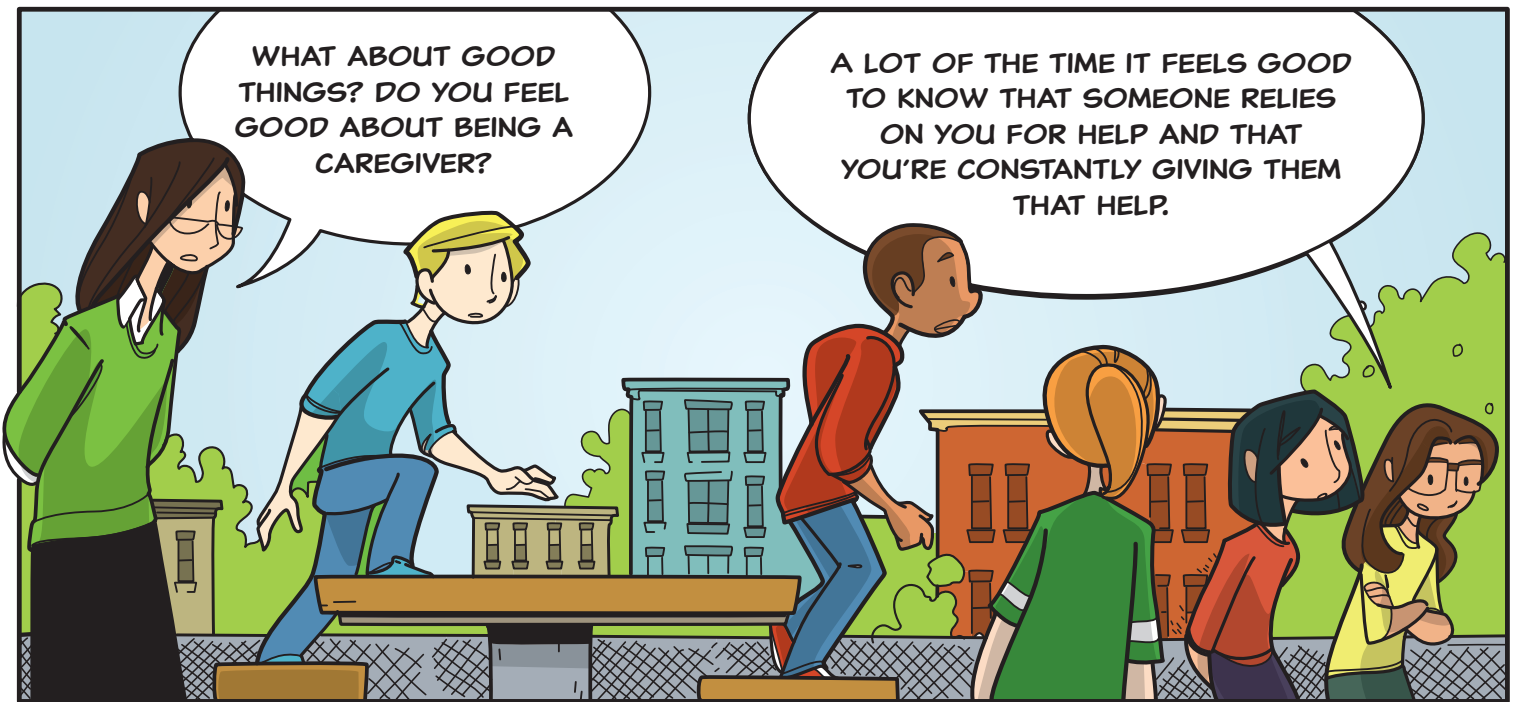
WHO CAN WE ASK TO HELP US KNOW WHAT TO DO?

MY MOM.

THE SOCIAL WORKER.

THE DOCTOR.

YES! GREAT IDEAS. CAREGIVING IS TOUGH. SO ALWAYS ASK FOR HELP. AND DON'T FORGET ABOUT THE ALS ASSOCIATION.



WHAT ABOUT GOOD THINGS? DO YOU FEEL GOOD ABOUT BEING A CAREGIVER?

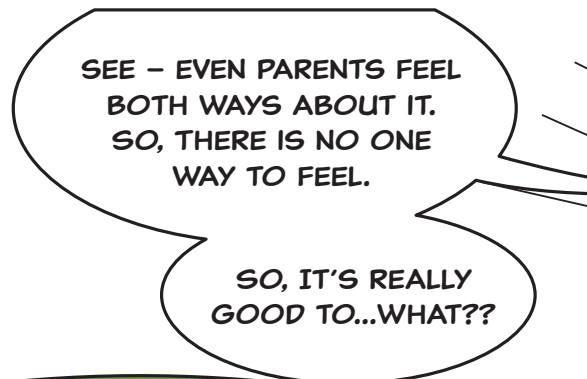
A LOT OF THE TIME IT FEELS GOOD TO KNOW THAT SOMEONE RELIES ON YOU FOR HELP AND THAT YOU'RE CONSTANTLY GIVING THEM THAT HELP.



THANK YOU, YASMINE. IT CAN FEEL GOOD TO KNOW YOU'RE HELPING SOMEONE. EVER WONDER WHAT YOUR PARENTS THINK? WE ASKED SOME ADULTS WITH ALS WHAT IT IS LIKE, AND THIS IS WHAT ONE PERSON SAID:



"I FEEL SAD THAT THEY ARE HAVING TO EXPERIENCE ME LIKE THIS AT SUCH A YOUNG AGE, BUT PROUD THAT THEY ARE CARING. MY KIDS DO IT BECAUSE THEY WANT TO, NOT BECAUSE THEY HAVE TO."



SEE - EVEN PARENTS FEEL BOTH WAYS ABOUT IT. SO, THERE IS NO ONE WAY TO FEEL.

SO, IT'S REALLY GOOD TO...WHAT??



TALK ABOUT IT!

THE NEXT TOPIC REALLY REQUIRES TALKING...

CHAPTER 5:
DEATH, DYING,
GRIEF, AND
LOSS

THIS CAN BE A TOUGH CONVERSATION. HAVE ANY OF YOU TALKED ABOUT DEATH OR DYING WITH YOUR MOM, YOUR DAD, OR YOUR FAMILY?

UNLESS SHE BRINGS IT UP, LIKE, I'M NOT GONNA BRING IT UP...

'CAUSE I DON'T WANNA MAKE HER ANY SADDER THAN SHE ALREADY IS.

THANK YOU, CARRIE. YES, IT CAN MAKE US ALL SAD TO TALK ABOUT DEATH, OR EVEN TO THINK ABOUT LOSING YOUR FAMILY MEMBER.

THIS IS REALLY TOUGH. SO, IF YOU WANT TO STOP FOR A MINUTE, THAT'S OK.

SHOULD WE GO ON?

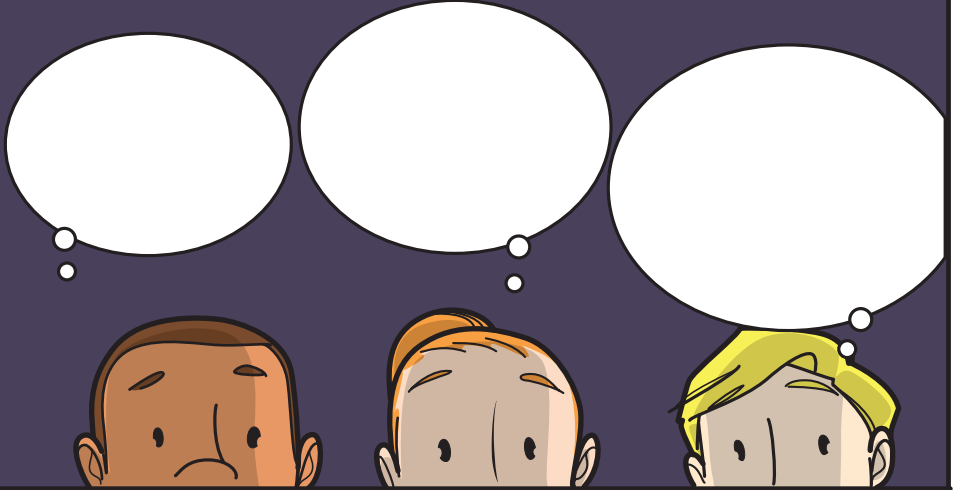
YES.

OK, WHILE IT'S REALLY TOUGH, ONE DAY, WE ARE ALL GOING TO DIE. BUT SOME PEOPLE MAY DIE BEFORE OTHER PEOPLE, INCLUDING PEOPLE LIVING WITH ALS. IT CAN BE SCARY TO THINK ABOUT DEATH.

(THAT WORD...AGAIN!)



WHAT DOES DEATH LOOK LIKE TO YOU?



IT'S OK TO NOT KNOW, OR TO BE A LITTLE AFRAID. I MEAN, AFTER ALL, WE ARE STILL HERE AND DON'T KNOW WHAT IT'S LIKE. IT CAN ALSO BE SAD BECAUSE YOU'RE LOSING SOMEONE YOU KNOW AND LOVE.

DOES ANYONE HAVE ANY QUESTIONS?

WHAT WILL IT LOOK LIKE WHEN SHE DIES?

WILL WE ALL STAY IN OUR HOME?

WHAT WILL HAPPEN TO ME WHEN HE DIES?

WHERE WILL WE LIVE AFTER MY MOM DIES?

WHAT WILL THE SERVICES OR FUNERAL LOOK LIKE?

WILL I BE THERE WHEN HE DIES?

WILL ANYONE BE WITH US AS A FAMILY?



WOW! THESE ARE ALL GREAT QUESTIONS! SOME TOUGH ONES, TOO. THESE ARE IMPORTANT THINGS TO ASK YOUR PARENTS. IT MAY BE HARD FOR THEM, TOO, BUT IT'S GOOD TO KNOW YOU ALL WANT TO HELP EACH OTHER.



LET'S CHECK IN WITH BELLA AND SEE HOW SHE FELT WHEN HER DAD DIED.

WHEN DAD DIED, I KNEW WHAT WAS GOING ON AND KNEW WHY. IT WAS SOMETHING THAT WAS, I GUESS, EXPECTED, AT LEAST FOR ME.

I KNEW A FEW DAYS AGO SOMETHING WAS GOING TO HAPPEN. HE SEEMED MORE SPACED OUT THAN HE USUALLY DID, AND WASN'T TALKING AS MUCH, EVEN WITH HIS COMPUTER. AND DAD LIKED TO STAY UP REALLY LATE. SO, WHEN HE WAS TIRED EARLY, IT WAS WEIRD. THEN WHEN HE DIED, I DIDN'T KNOW HE DIED. I ACTUALLY WOKE UP TO MY SISTER CRYING, AND I WAS SLIGHTLY ANNOYED BECAUSE I USUALLY DON'T LIKE BEING WOKEN UP. BUT THEN ONCE THE AMBULANCE CAME, I KNEW. I SAT IN THE BEDROOM WITH MY DOG WHO WAS EXTREMELY CONFUSED.

IT WAS SAD AND WEIRD NOT HEARING 'HI SOURPUSS' (A NICKNAME MY DAD ALWAYS USED FROM MY 3RD GRADE PLAY) EVERY TIME I WALKED IN THE DOOR, BUT IT WAS ALSO KIND OF RELIEVING, NOT HAVING TO DO THE SUCTION MACHINE. (WHICH I ALWAYS ACCIDENTALLY DROPPED, SO SORRY)

IT WASN'T EXTREMELY HAPPY, BUT YOU SOON THINK ABOUT IT IN A BETTER WAY. I GUESS.



BELLA'S STORY IS SOMETHING THAT MANY OF YOU MAY GO THROUGH. THE FEELING OF BEING SAD, SCARED, AND NOT KNOWING WHAT IS GOING ON. WHEN WE LOSE SOMEONE, WE FEEL THE GRIEF OF THAT LOSS.



GRIEF?

WHAT IS THAT?

GRIEF IS SADNESS, ANGER, FEAR, LOSS – ALL THESE THINGS IN ONE. EVERYONE CAN FEEL GRIEF.


HAVE ANY OF YOU LOST SOMEONE?

MY GRANDMA DIED, AND I WAS SO SAD. I KINDA CRIED A LOT. BUT MY MOM SAID THAT WAS OK.

TRISTAN, YES, THAT IS OK. GRIEF IS REAL AND COMES IN LOTS OF WAYS.

MANY PEOPLE THINK GRIEF ONLY HAPPENS AFTER SOMEONE DIES, BUT DID YOU KNOW IT CAN HAPPEN EVEN BEFORE SOMEONE DIES? HOW MANY OF YOU FEEL LIKE YOUR LOVED ONE WITH ALS HAS CHANGED?

WHAT ABOUT FEELING LIKE YOU HAVE "LOST" A BEST FRIEND OR PARENTS EVEN THOUGH THEY ARE STILL HERE?



THESE LOSSES ARE ALL PART OF GRIEF – AND VERY NORMAL.

REMEMBER WHEN YASMINE SAID SHE DID NOT FEEL LIKE A "NORMAL" FAMILY ANYMORE? WELL, THIS IS A LOSS, AND SHE IS GRIEVING THE LOSS OF THE FAMILY SHE HAD WHILE EVERYTHING IS CHANGING.

WELL, MY DAD CAN'T SWALLOW ANYMORE.

AND MY MOM CAN'T TALK AND I MISS HER VOICE SO MUCH.

WHAT DOES IT FEEL LIKE WHEN THESE THINGS CHANGE?

IT FEELS LIKE WE JUST GET USED TO SOMETHING, THEN ANOTHER THING GOES WRONG.

CONFUSED.

SAD.

EVEN THOUGH WE FEEL THIS WAY WHEN THINGS CHANGE, THERE IS ALSO A SENSE OF ANTICIPATION OR EXPECTATION OF THE LOSS AND THE EVENTUAL GRIEVING PROCESS. WHO CAN YOU TALK TO?

MY MOM.

MY TEACHER.

MY BEST FRIEND.

I KNOW WE ARE SUPPOSED TO TALK ABOUT IT, BUT WHAT IF I DON'T WANT TO?

GOOD QUESTION.

BESIDES TALKING, WHAT ELSE CAN YOU DO?

HOW ABOUT DOING SOME ART - DRAWING OR USING CLAY FOR POTTERY?

GREAT! IF YOU LIKE TO WRITE - HOW ABOUT WRITING WHAT YOU FEEL? IT'S LIKE YOU'RE TALKING, BUT WITHOUT THE ACTUAL TALKING PART.

OVERALL, LOSING SOMEONE IS HARD AND YOU WILL FEEL SAD. THAT'S TOTALLY NORMAL.

YOU CAN DO A LOT OF THINGS TO DEAL WITH YOUR FEELINGS. JUST DON'T KEEP THEM INSIDE.

WE KNOW, WE KNOW...
TALK ABOUT IT!

REMEMBER BELLA?
HERE'S SOMETHING SHE DREW.

SHE NEEDED TO EXPRESS HER FEELINGS, AND SOMETIMES THAT'S JUST HARD TO DO. SO, SHE DREW HERSELF UNDER THE UMBRELLA, AND ALL THE RAINDROPS ARE HER FEELINGS. SHE SHARED THAT WITH ME, AND I AM SHARING IT WITH YOU. THIS IS JUST ONE WAY TO EXPRESS YOUR FEELINGS.

I DON'T WANT TO FORGET MY DAD WHEN HE DIES.

OF COURSE NOT, AND YOU NEVER WILL. MY DAD DIED A LONG TIME AGO, AND I THINK OF HIM ALL THE TIME. SOMETIMES I EVEN STILL GET SAD, WHICH IS OK. SEE, LOSING SOMEONE DOESN'T HAVE A TIMELINE. YOU CAN STILL MISS THEM EVEN AS YOU GROW UP AND MEET NEW PEOPLE, GO TO SCHOOL, AND GET A JOB. YOU WILL ALWAYS REMEMBER THEM.



SO WE ARE ALMOST AT THE END...HAS THIS BEEN HELPFUL?

YES!!

I AM SO GLAD! IT HAS BEEN GREAT TO TALK WITH YOU ALL - AND NOW YOU KNOW EACH OTHER.

HOW CAN WE KEEP IN TOUCH WITH EACH OTHER?

ARE YOU GOING TO THE ALS MEETING NEXT WEEK?

WHAT IS YOUR PHONE NUMBER?

I'M BRIAN, WHAT IS YOUR NAME?

THE ALS ASSOCIATION CHAPTERS IN YOUR AREAS ARE DOING A LOT TO MAKE SURE KIDS LIKE YOU KEEP IN TOUCH. CONTACT THEM, AND THEY CAN LET YOU KNOW WHAT PROGRAMS OR SUPPORT THEY HAVE FOR YOU AND YOUR FAMILY.

We're so thankful for the young people who shared their stories and gave their time to help create this book. Other books in the informational series for kids and young adults include *The ALS Experience: It's Different and Hard* and *School, Friends, Work, and ALS: A Young Adult Guide to Balancing Life with ALS*.

The ALS Association is the only national nonprofit organization fighting ALS on every front. The Association's mission is to discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.

For more information, visit www.alsa.org.



