

Real kids talk about

MND

Feeling normal, sad and
different



ALS Association

MND Scotland

Guide for youth 7-12.



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Dr. Kavanaugh is a licensed clinical social worker (LCSW) and professor of social work. She has over 25 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**

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 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 in Scotland from MND Scotland - visit <https://mndscotland.org.uk/>



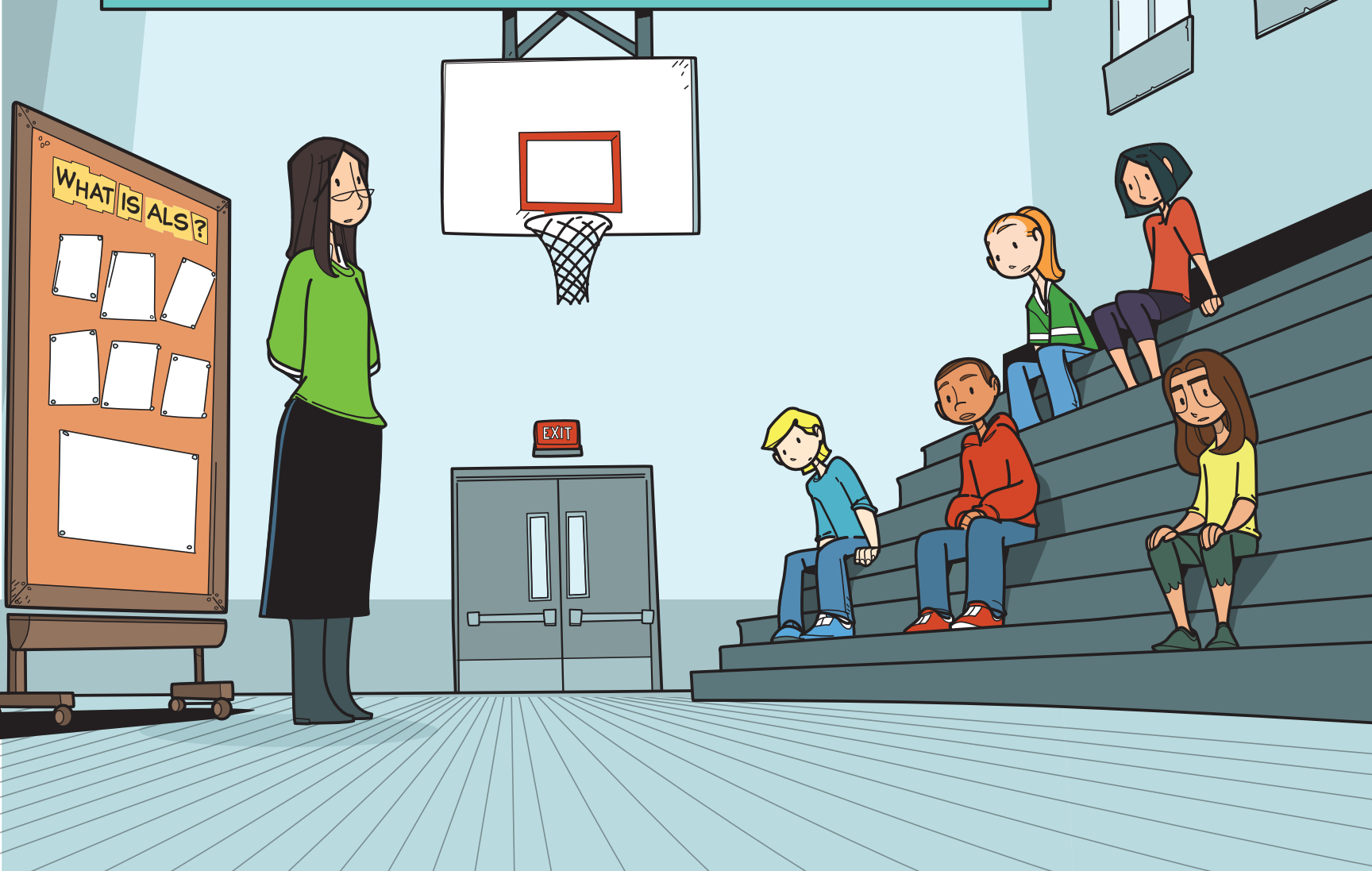
WHY DID WE WRITE THIS BOOK?

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

DR. MELINDA KAVANAUGH HAS CONDUCTED LOTS OF RESEARCH WITH FAMILIES – INCLUDING MND. SHE HAS ASKED PARENTS AND KIDS WHAT THEY NEED, AND WHAT THEY KNOW OR DON'T KNOW ABOUT MND. BECAUSE SHE IS IN THE US, THEY USE ALS IN PLACE OF MND. SO YOU MAY SEE ALS IN THE BOOK. BUT DON'T WORRY, IT IS THE SAME.

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

WE LIKE GRAPHIC NOVELS AND HOPE YOU WILL TOO. IT CAN MAKE TALKING ABOUT MND A LOT EASIER. THANK YOU TO ALL THE FAMILIES WHO HELPED US AND TO BELLA – WHO SHARED HER STORY AND HER ART IN THIS BOOK!



CHAPTER 1:
WHAT IS MND?

BRIAN'S
MOM
HAS MND

AND
ALISON'S
DAD

CARRIE'S
MUM

TRISTAN'S
GRANDPA

AND FINALLY,
YASMINE'S
DAD

HI EVERYBODY!

TALKING ABOUT MND
CAN BE HARD FOR
FAMILIES TO DO.

WE WANT TO HELP YOU GET
TO KNOW MND A BIT BETTER
AND FIGURE OUT HOW TO
TALK TO YOUR FAMILY AND
FRIENDS ABOUT IT.

SO...

WHAT IS MND?

IT ATTACKS THE MUSCLES AND DESTROYS THEM.

YES, ALISON, THAT IS CORRECT!

MND 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 MND CAN'T USE THEIR ARMS LIKE THEY USED TO BECAUSE THE MUSCLES DON'T KNOW WHAT TO DO.



MY MUM CAN'T MOVE.

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

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

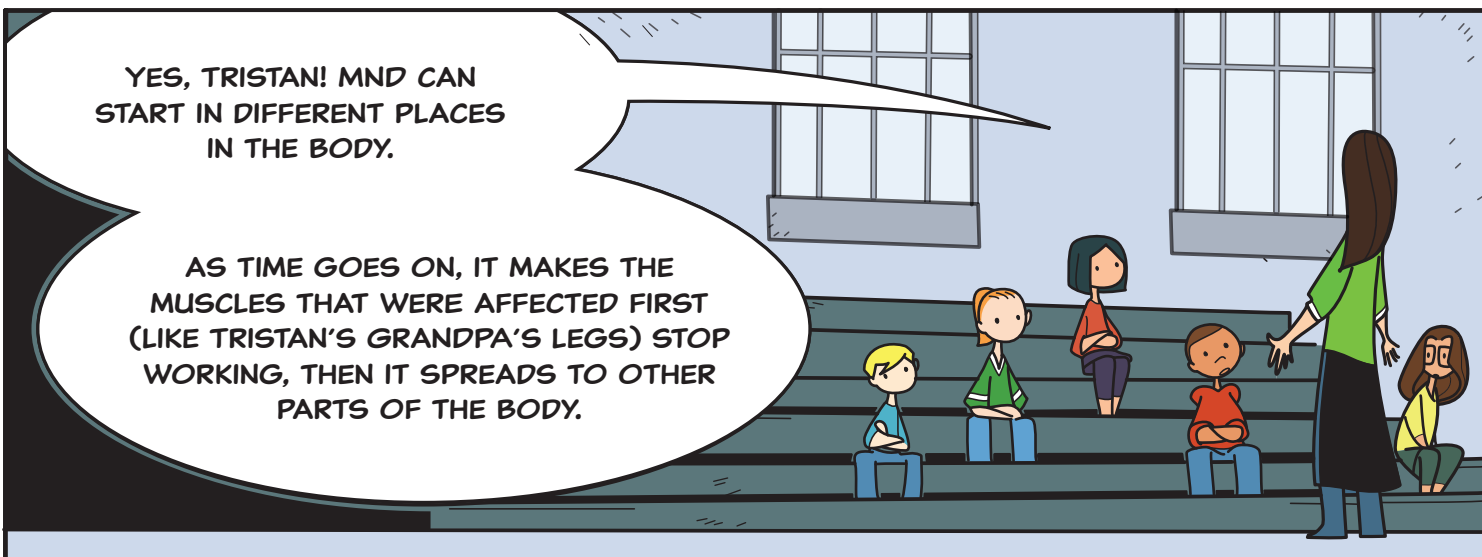
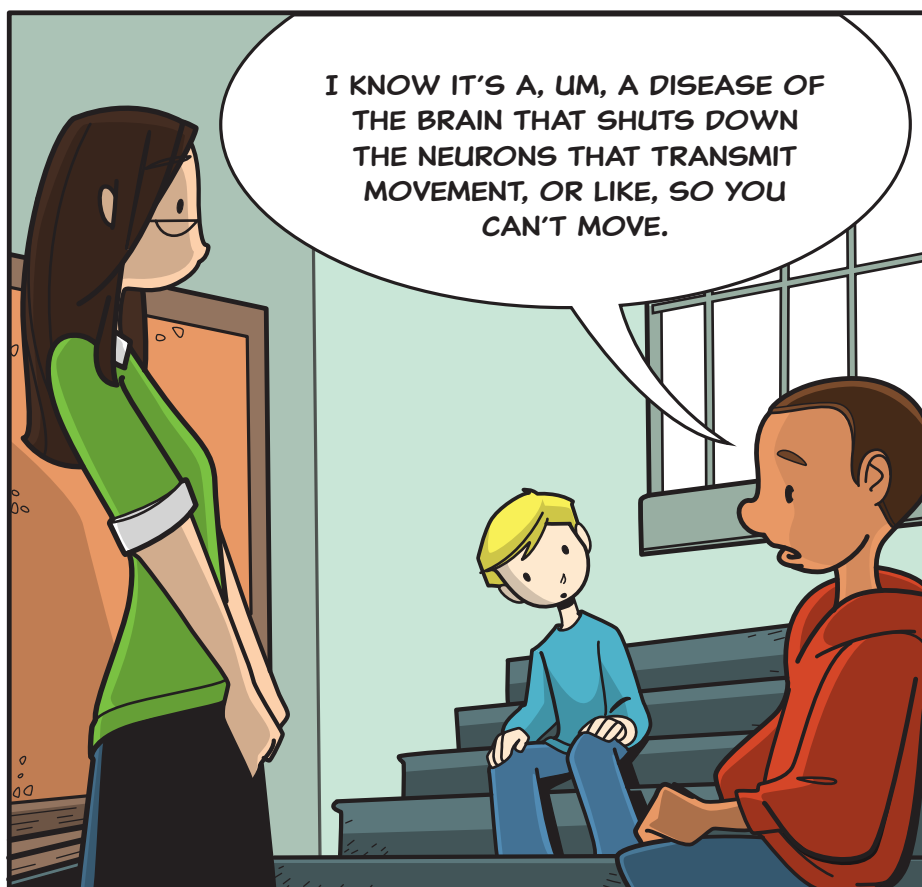
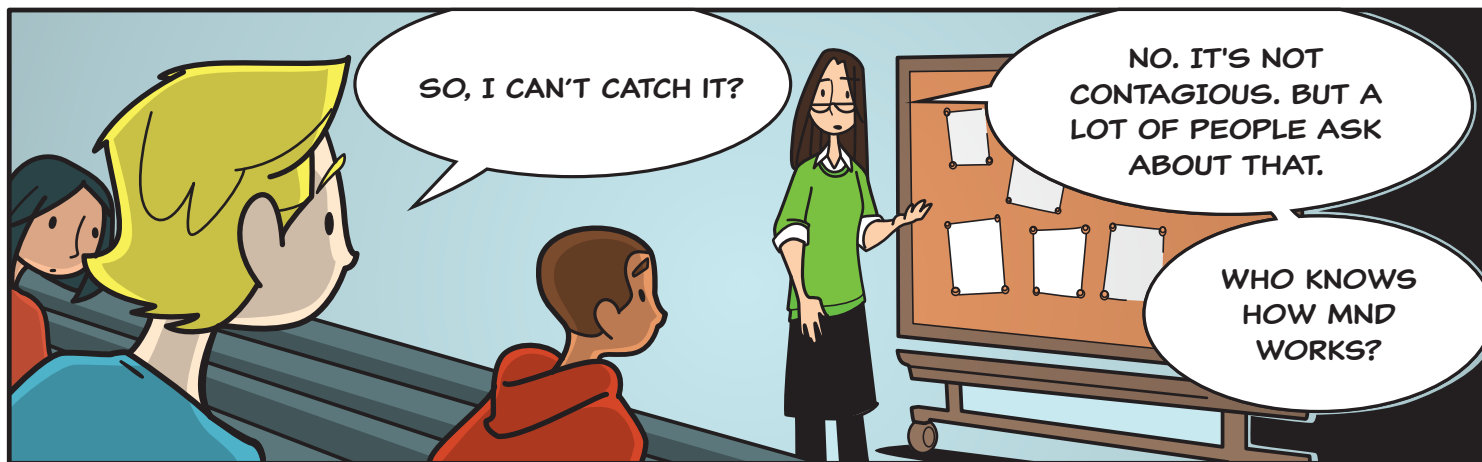
WHAT IS ALS

MND 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?

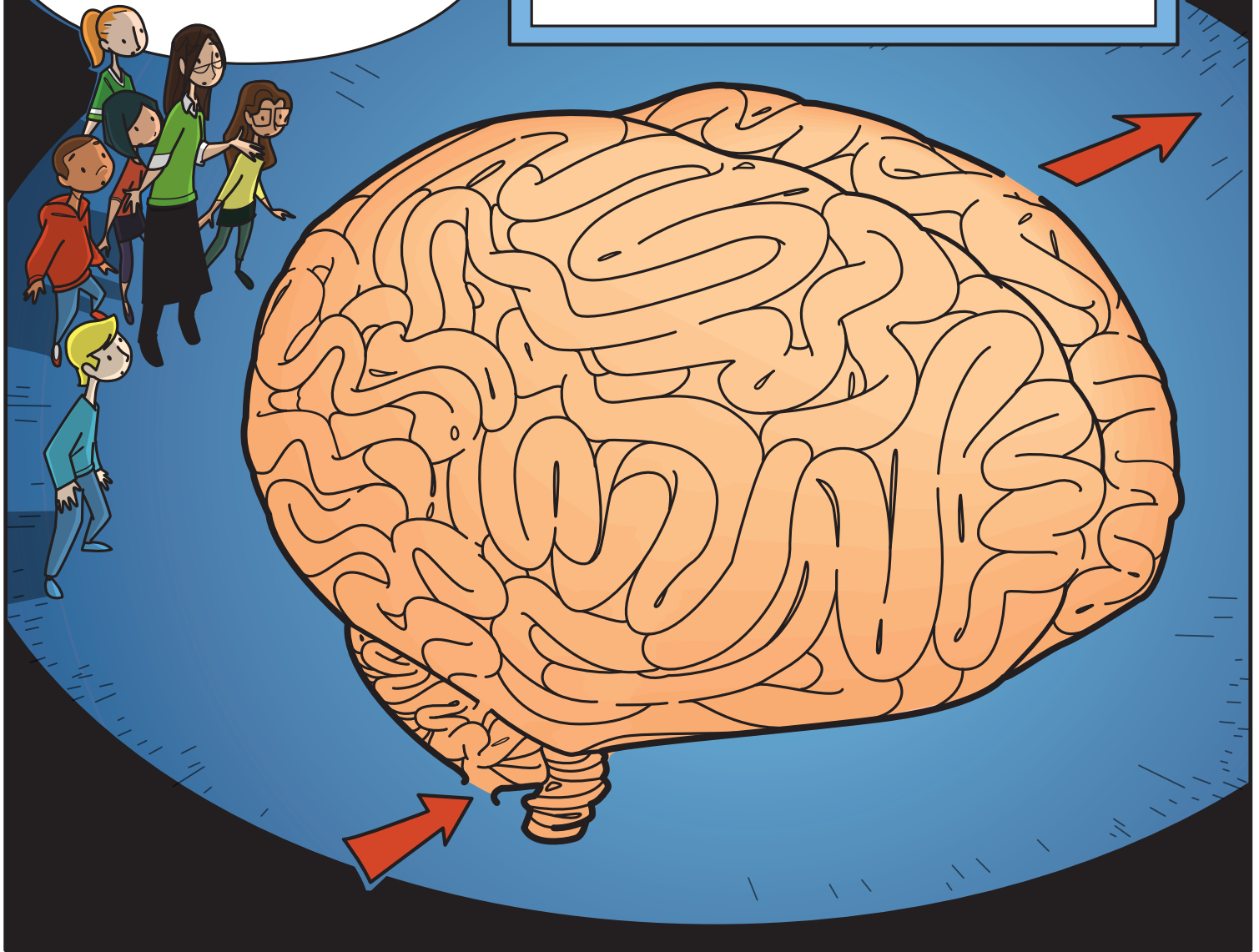
I THOUGHT ONLY GIRLS COULD GET IT.

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



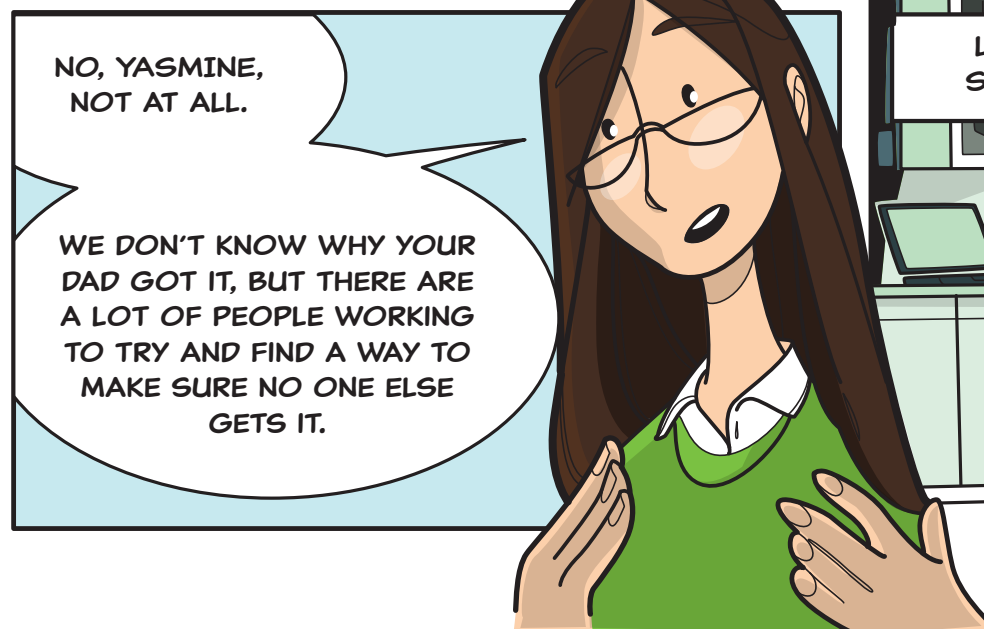
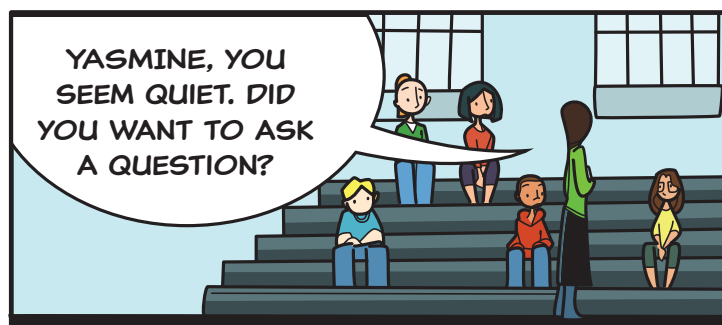
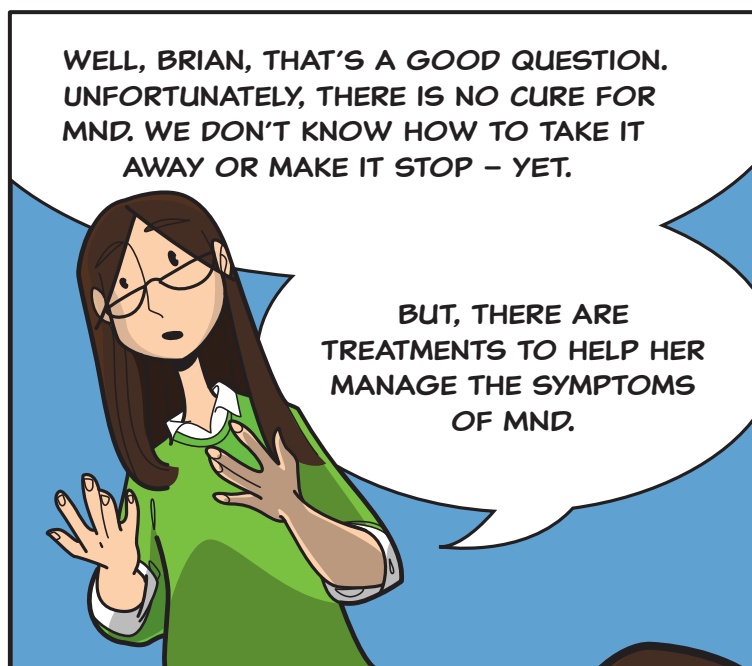
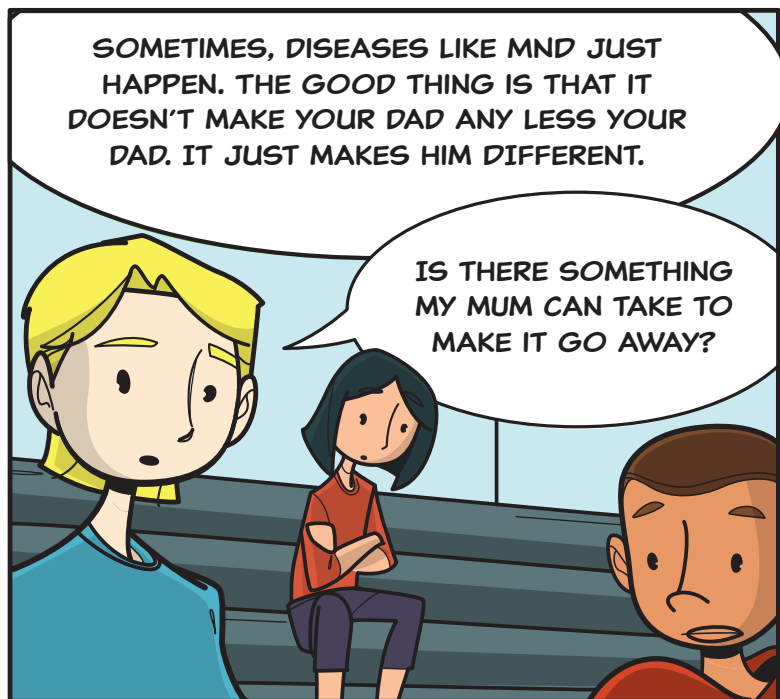
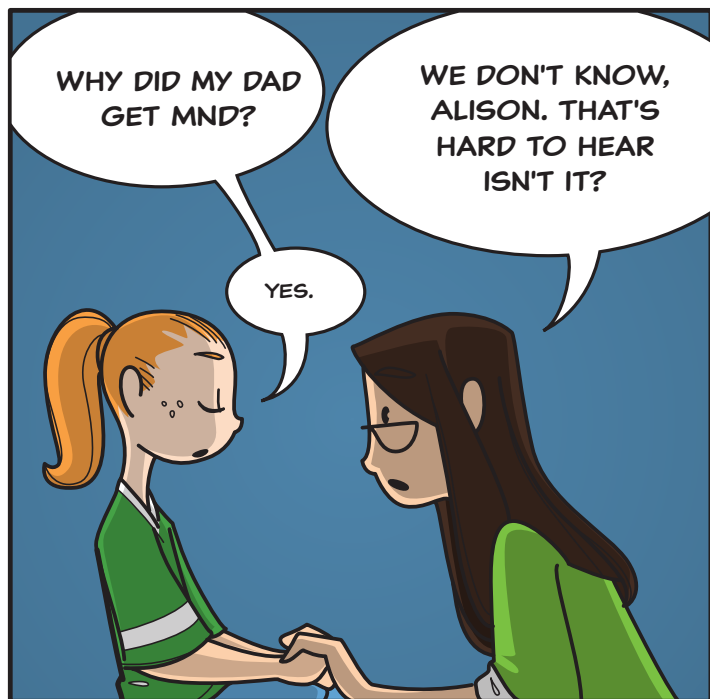
BRAINS ARE VERY COOL THINGS. THEY ARE THE CONTROL CENTER FOR HOW WE TALK, WALK, AND THINK.

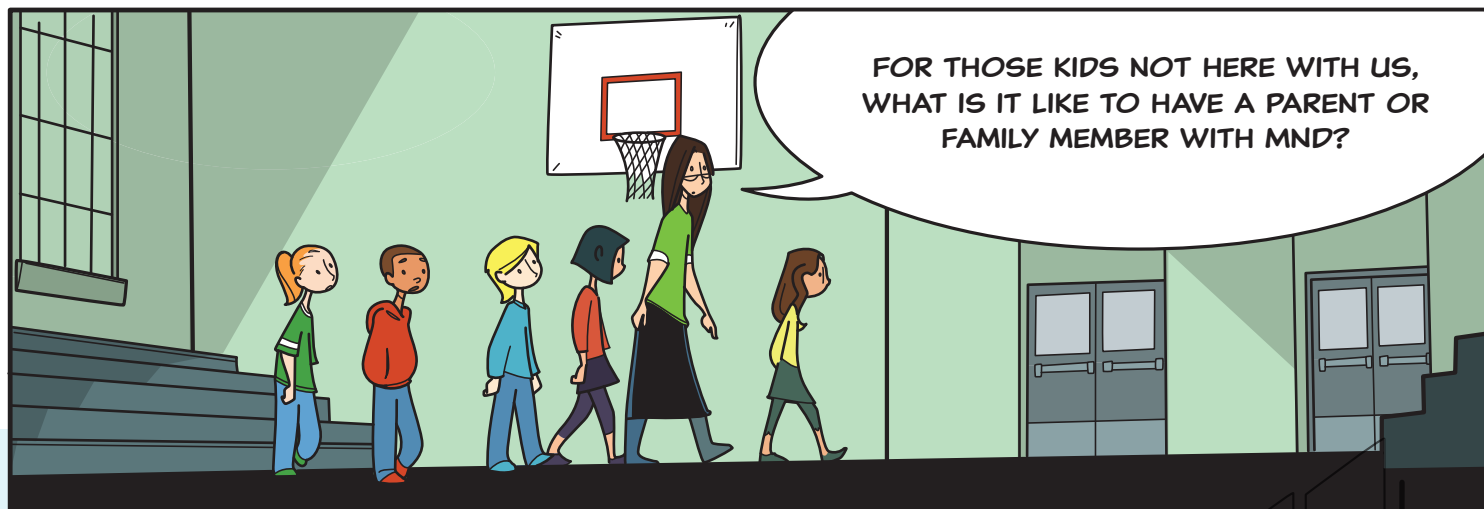
USE THIS MAZE TO WALK THROUGH THE BRAIN. SEE IF YOU CAN MAKE IT ALL THE WAY THROUGH!



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







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

IT'S PRETTY SCARY!

SCARY, HUH?

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

ALSO, WE DON'T KNOW
HOW LONG SOMEONE WILL
LIVE WITH MND. 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 MND



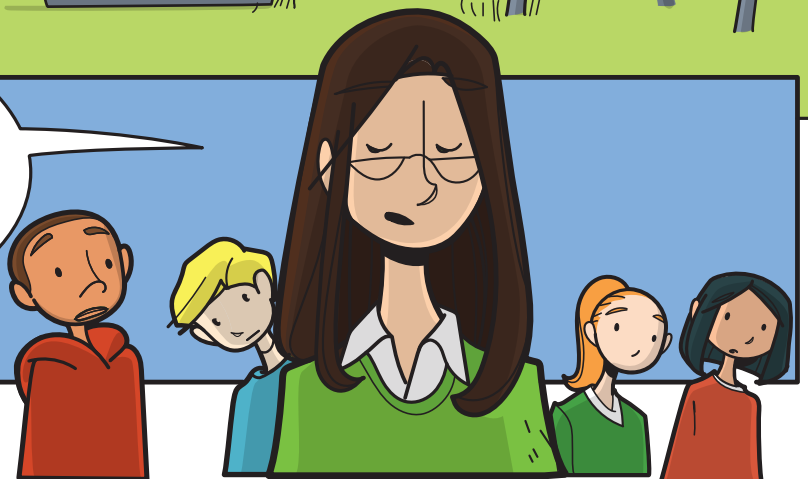
BELLA IS 11 YEARS OLD. HER DAD HAD MND. I SAY HAD, BECAUSE HE DIED JUST THIS YEAR. HER DAD DID NOT HAVE MND FOR VERY LONG, SO IT WAS REALLY HARD TO UNDERSTAND WHAT WAS HAPPENING.

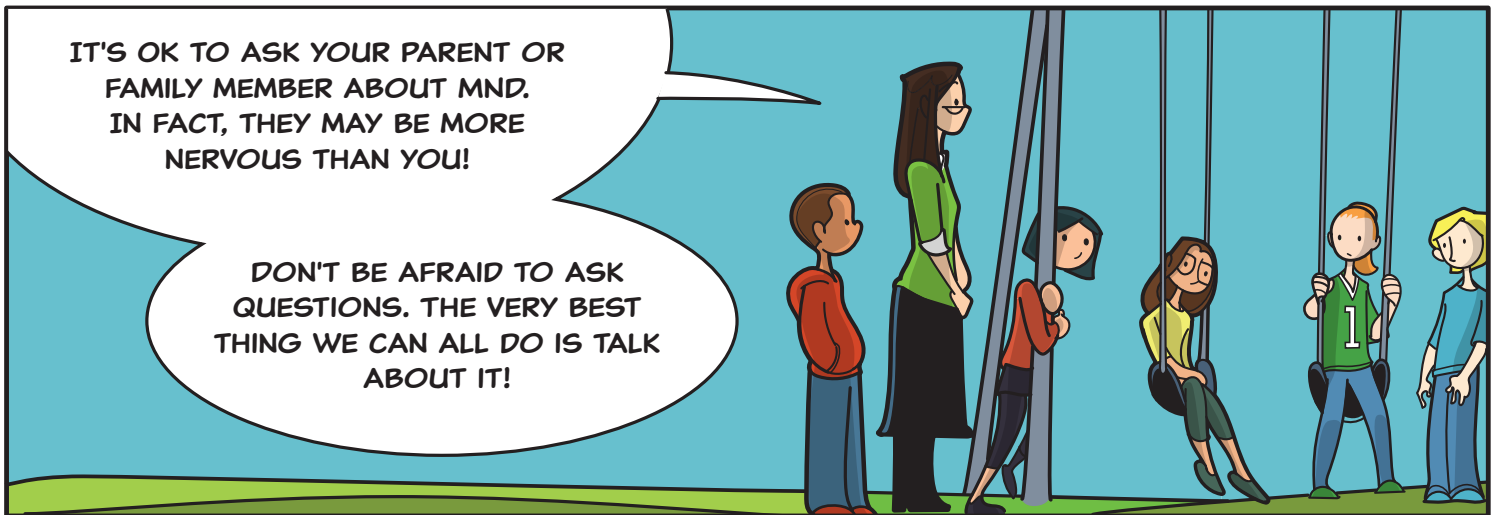
BELLA KNEW SOMETHING WAS GOING ON WHEN HER DAD WOULD FALL—A LOT. THEN HIS VOICE STARTED TO SOUND FUNNY. BELLA WAS REALLY CLOSE TO HER DAD, HE WOULD OFTEN TEASE HER AND JOKE AROUND WITH HER, SO SHE STARTED TO GET SCARED THAT SOMETHING REALLY BAD WAS HAPPENING.

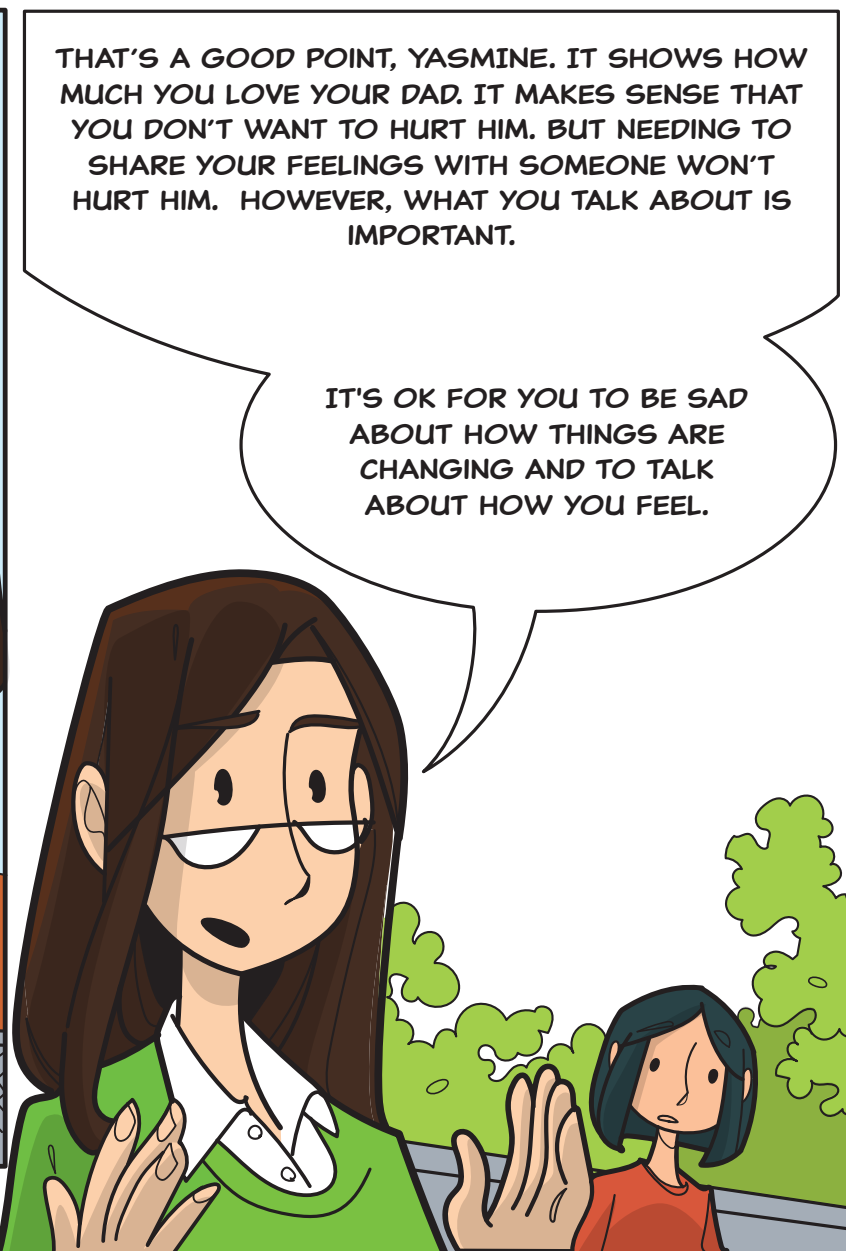
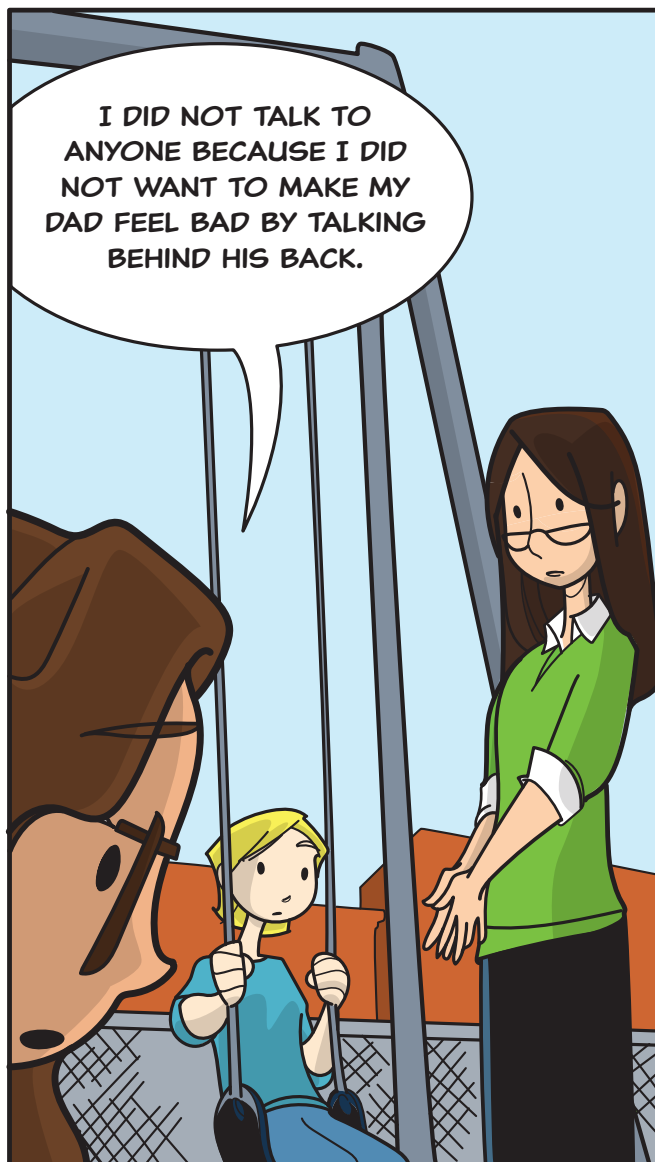
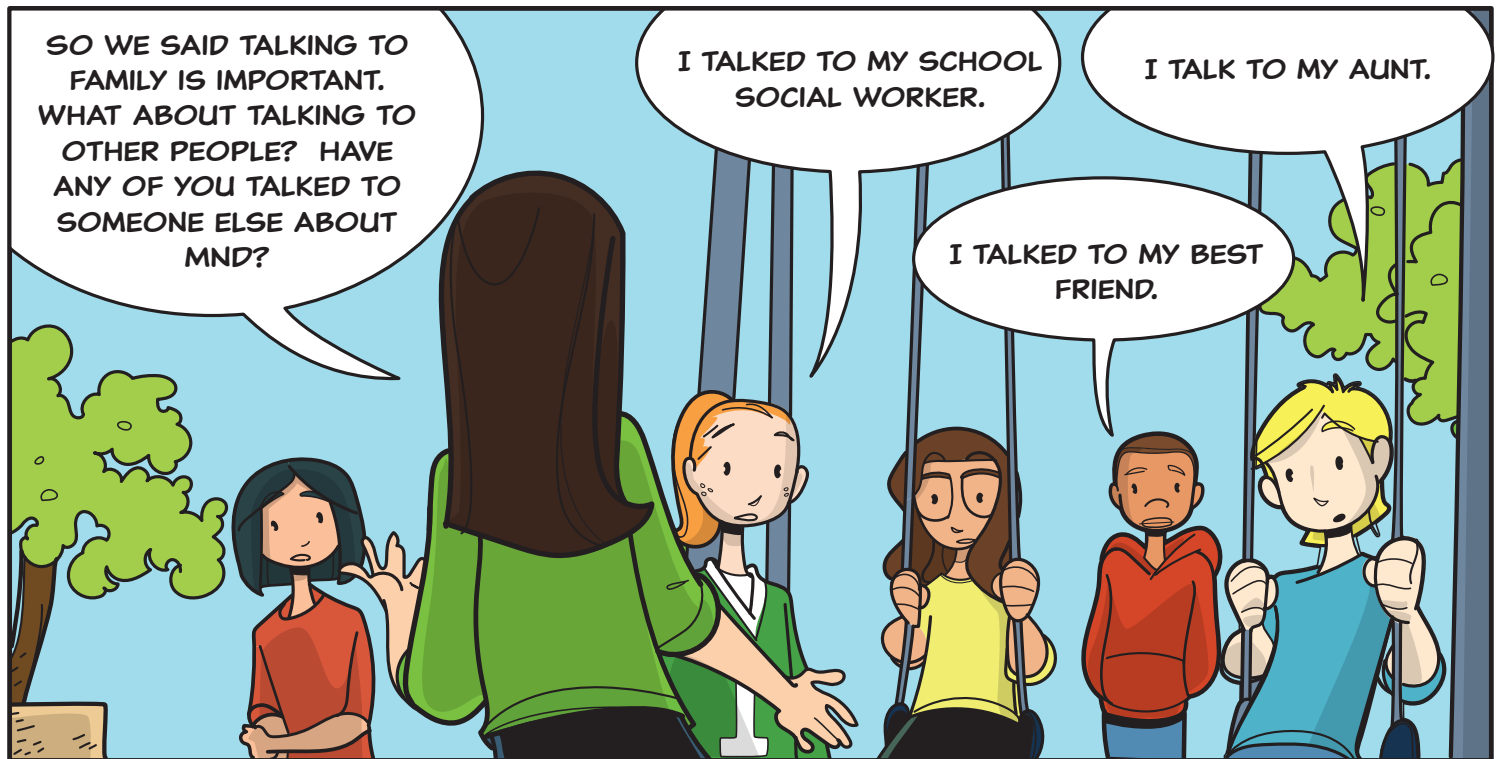
HER FAMILY DID NOT TALK TOO MUCH ABOUT WHAT WAS HAPPENING, BECAUSE THEY DID NOT WANT TO WORRY BELLA. THEY WENT TO A LOT OF DOCTORS, AND FINALLY GOT ONE WHO DIAGNOSED HER DAD WITH MND. BELLA SAYS GETTING THE DIAGNOSIS WAS DIFFICULT FOR HER BECAUSE SHE GETS ANXIOUS AND IS SOMETIMES AFRAID OF TALKING TO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

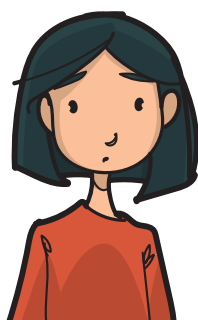
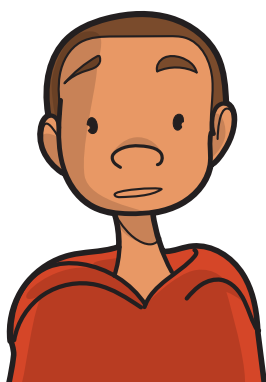
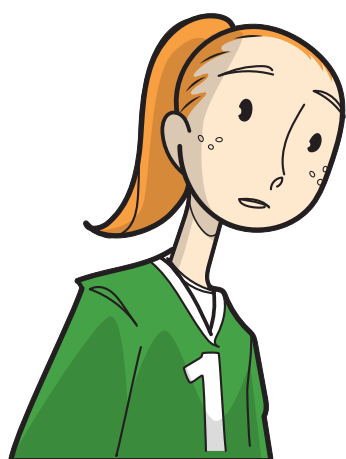
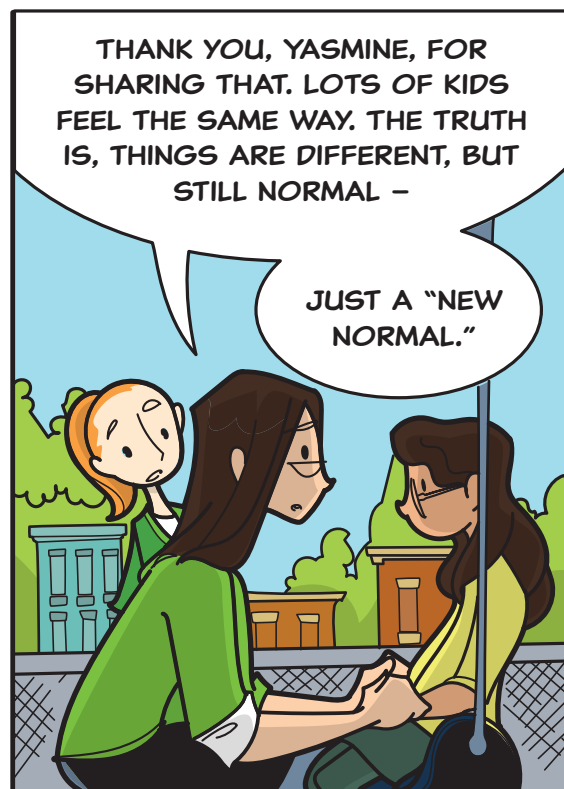
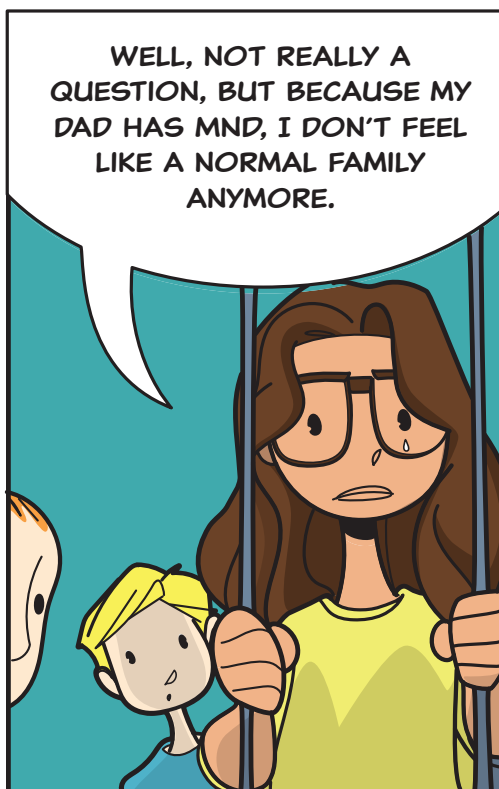
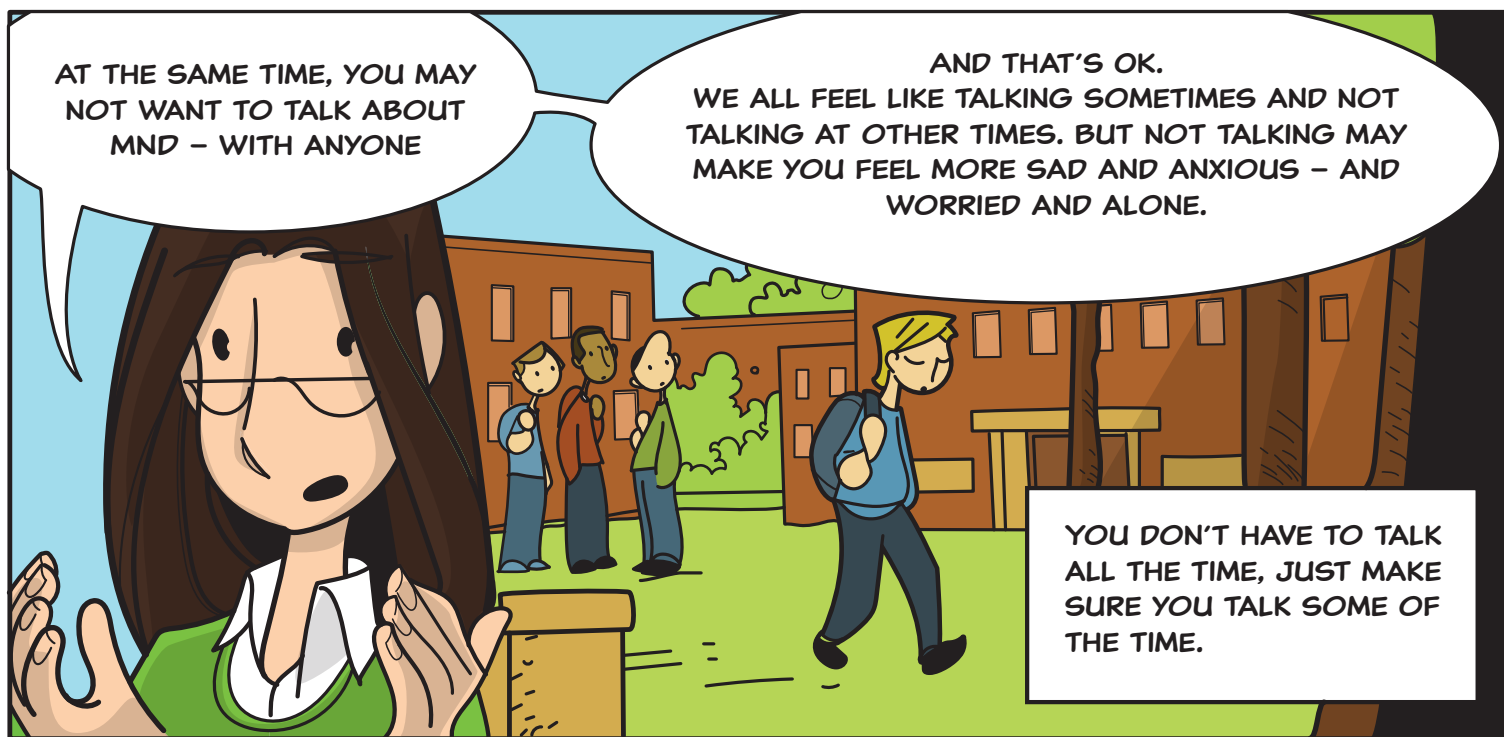


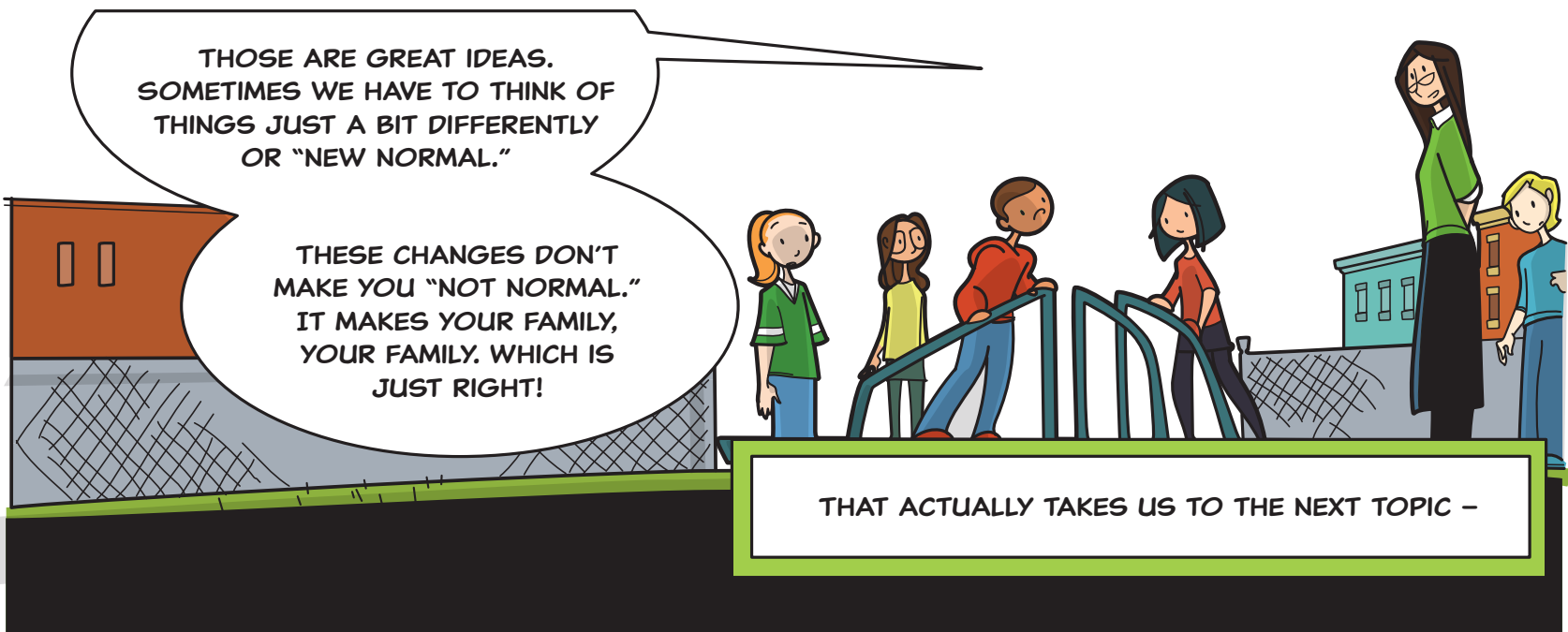
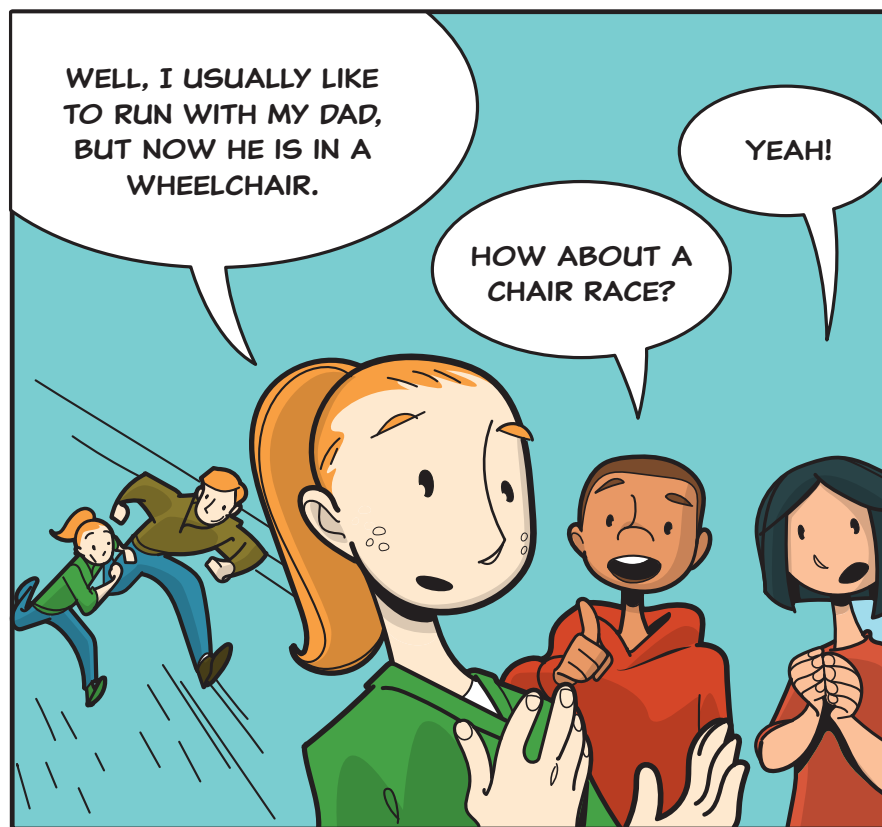
BELLA'S EXPERIENCE IS REALLY COMMON. SOMETIMES FAMILIES DON'T TALK BECAUSE THEY DON'T WANT TO UPSET EACH OTHER. BUT, LIKE BELLA, YOU PROBABLY HAVE LOTS OF QUESTIONS.











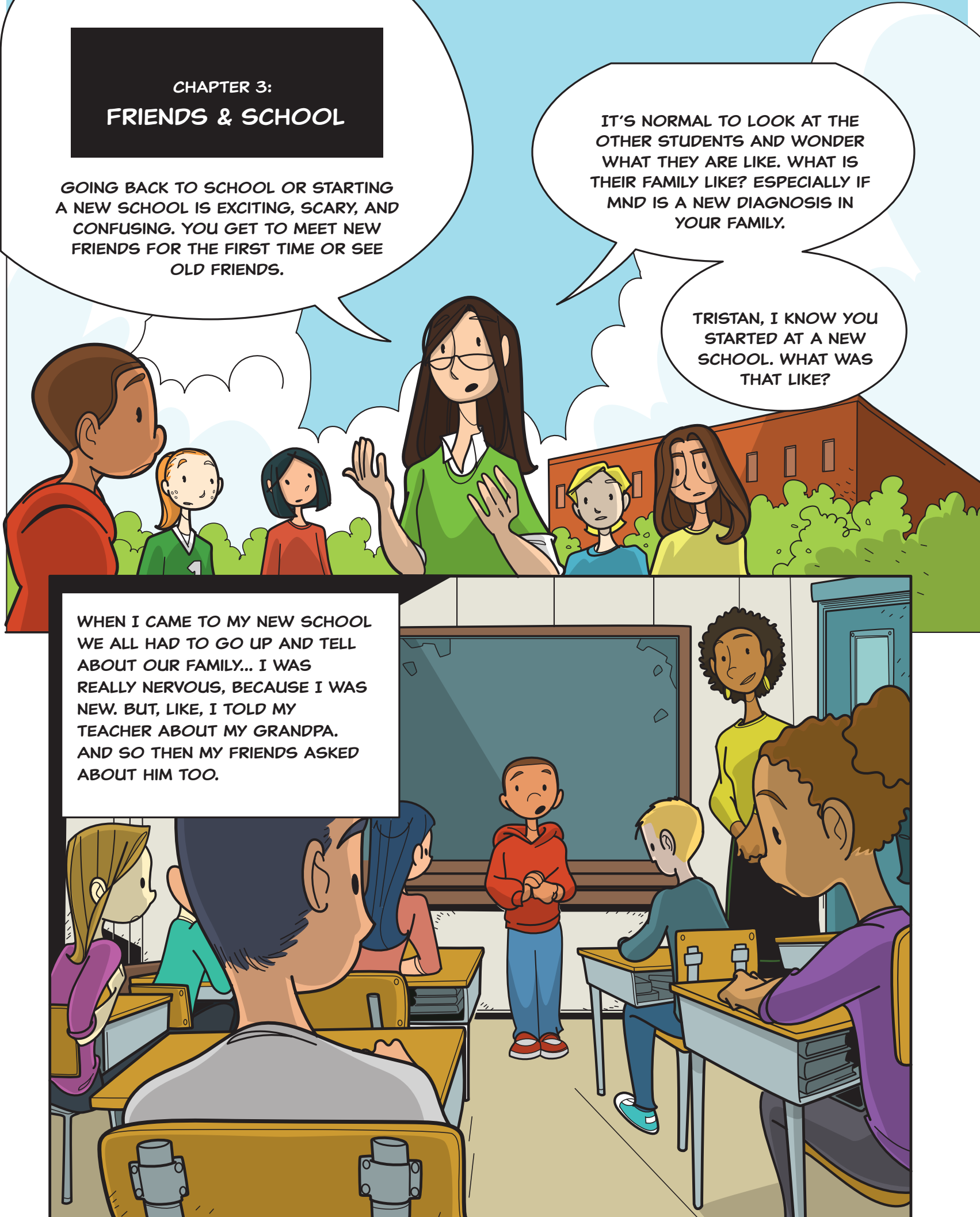
CHAPTER 3: FRIENDS & SCHOOL

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 MND 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.

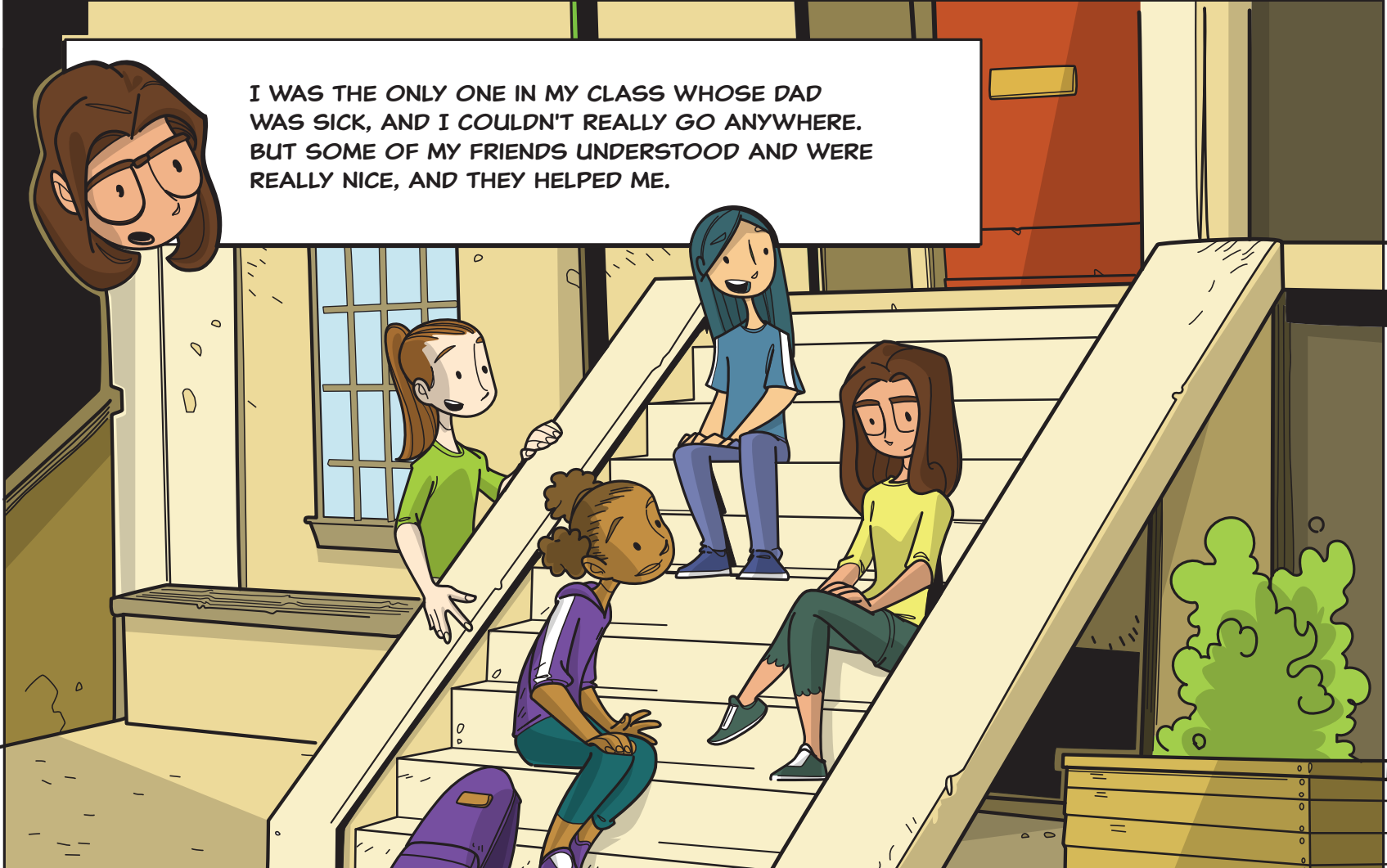
THAT'S GREAT ALISON. SHARING WITH THE SCHOOL IS IMPORTANT. HERE ARE SOME WAYS YOU AND YOUR PARENTS CAN THINK ABOUT TALKING TO YOUR SCHOOL.

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?

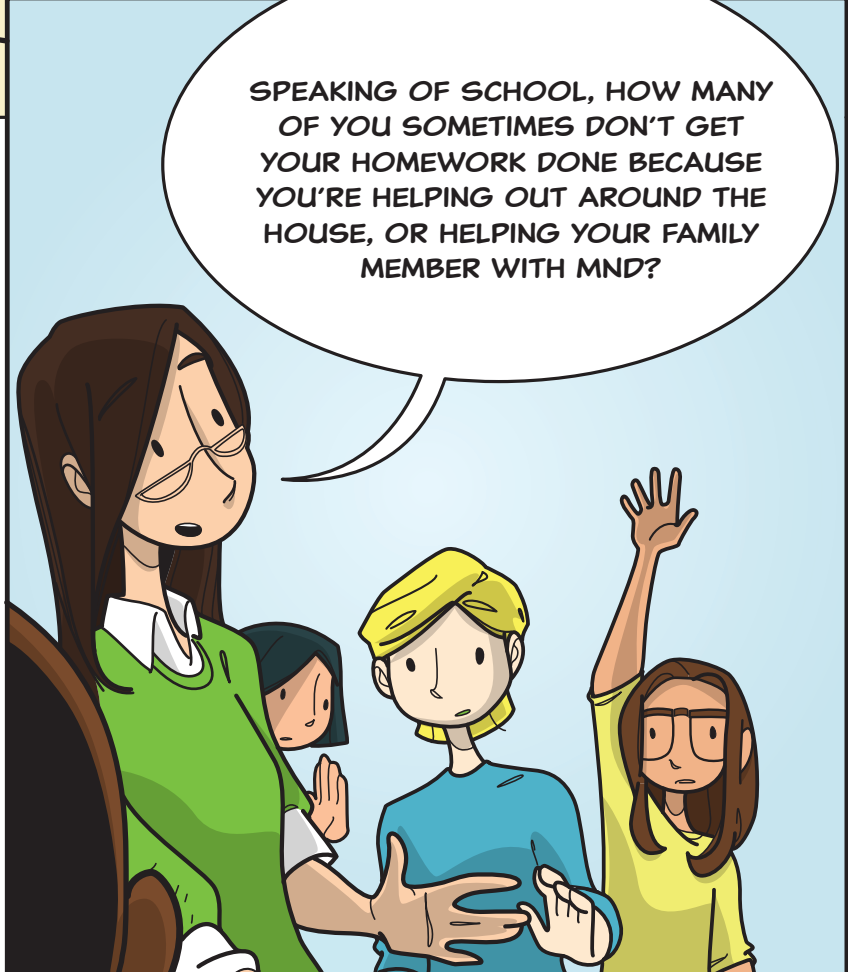
A large sheet of lined paper with horizontal lines for writing, featuring two binder holes on the left side.



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.

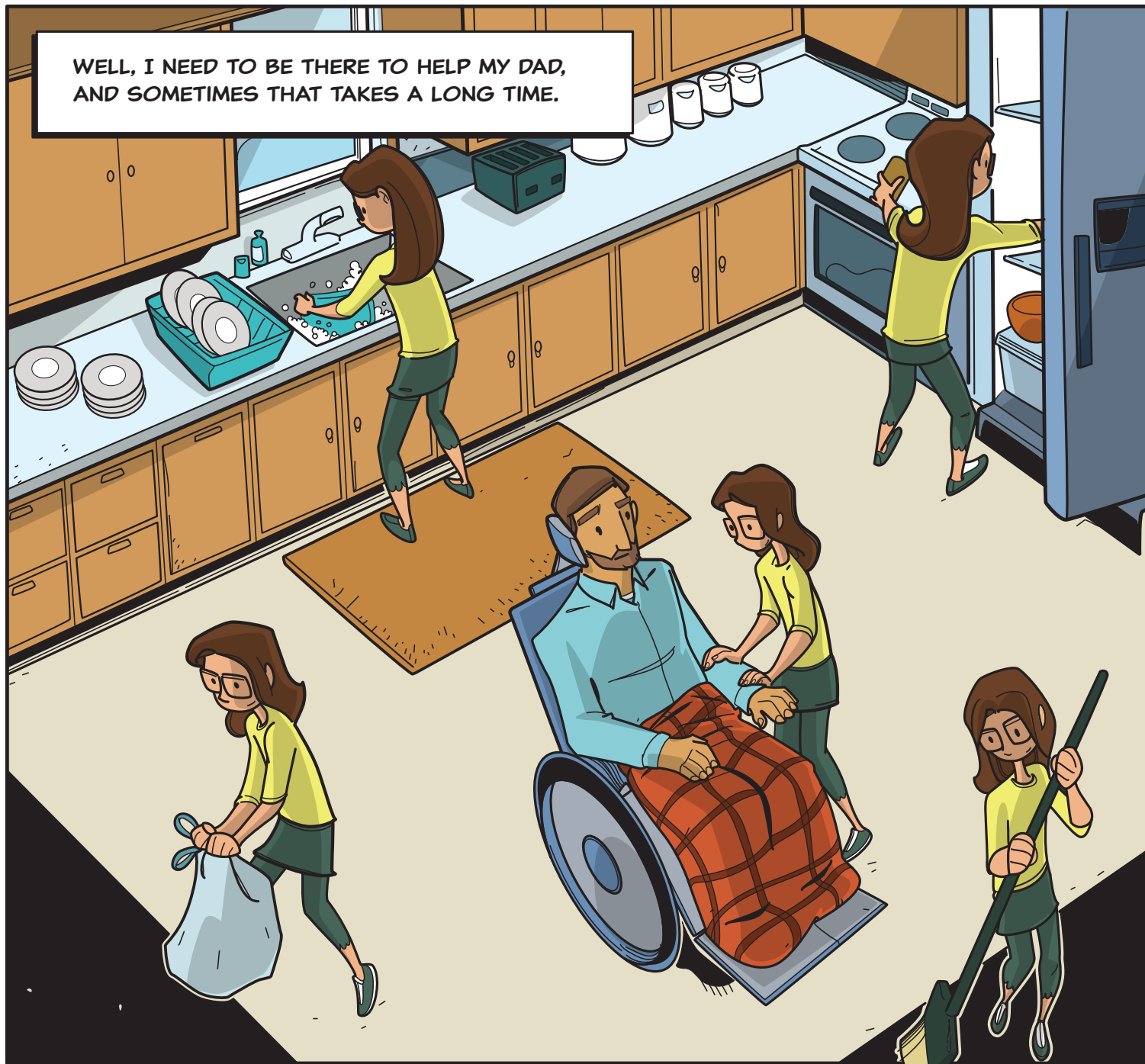


THANK YOU, YASMINE. TALKING TO OTHER KIDS ABOUT MND CAN BE HARD — SPECIFICALLY WHEN THEY DON'T HAVE A FAMILY MEMBER WITH MND. SO, WHEN YOU HAVE THE CHANCE, IT'S REALLY GOOD TO TALK ABOUT IT.

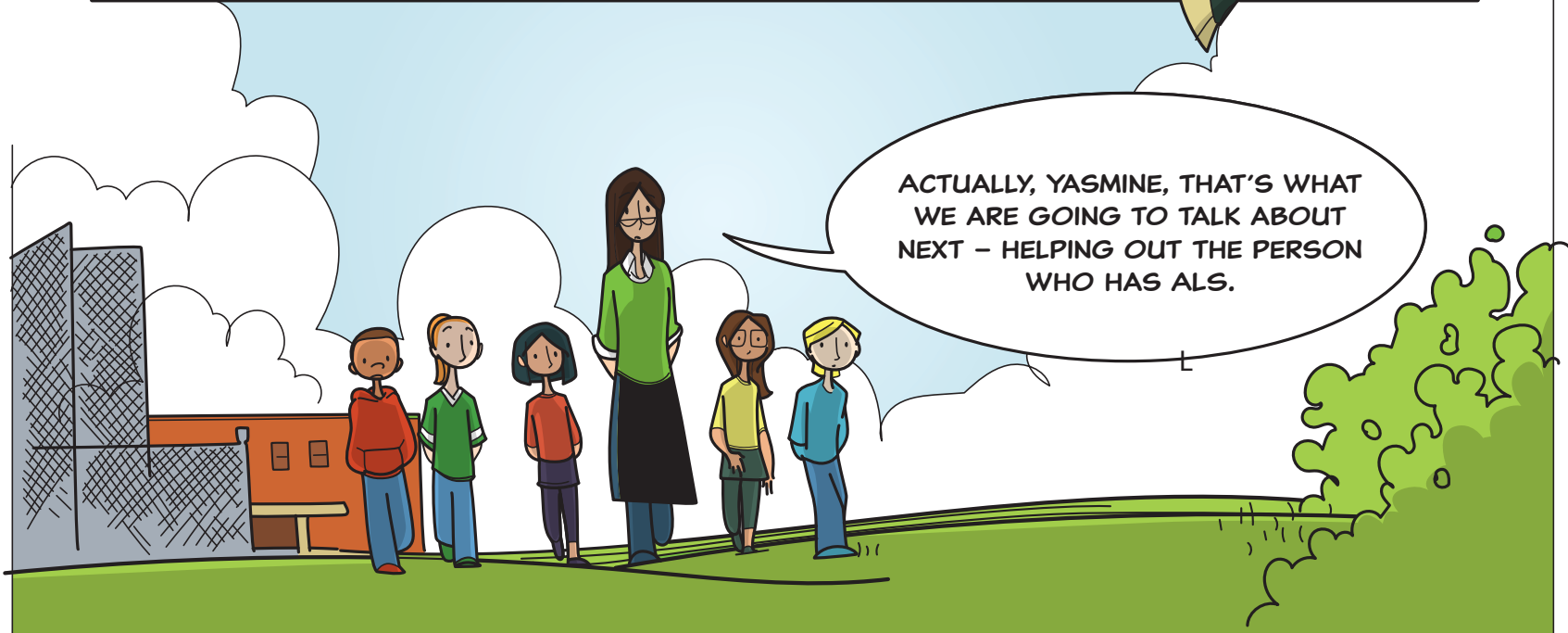


SPEAKING OF SCHOOL, HOW MANY OF YOU SOMETIMES DON'T GET YOUR HOMEWORK DONE BECAUSE YOU'RE HELPING OUT AROUND THE HOUSE, OR HELPING YOUR FAMILY MEMBER WITH MND?

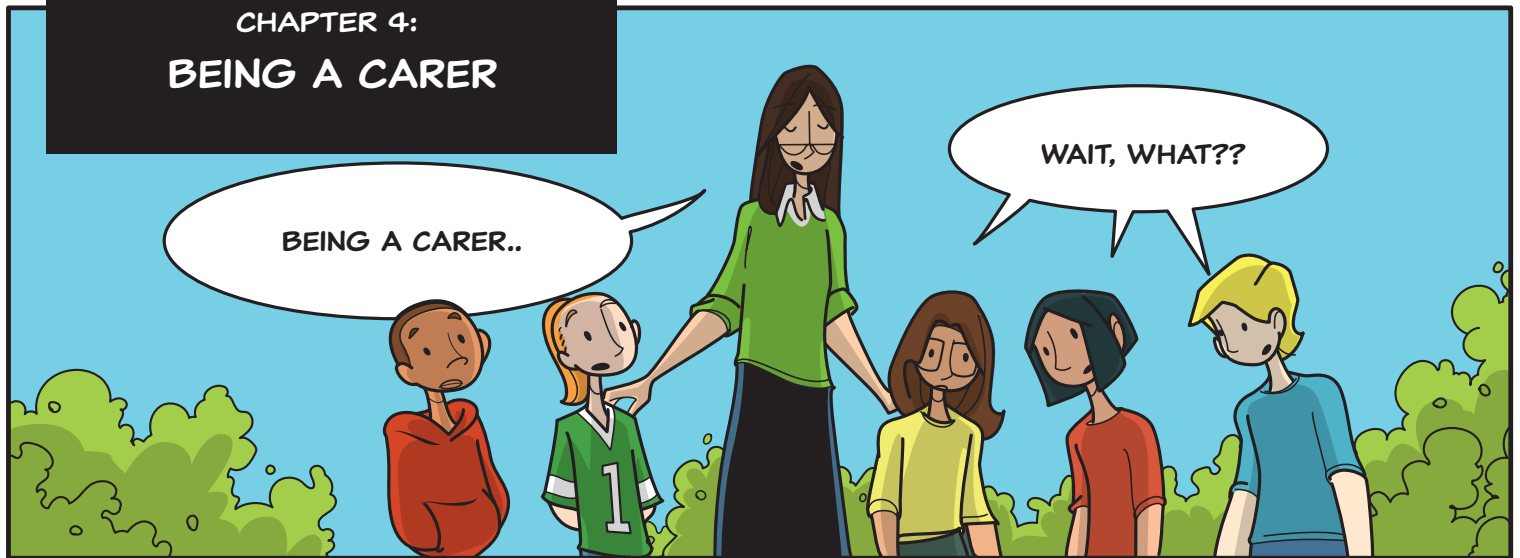
WELL, I NEED TO BE THERE TO HELP MY DAD,
AND SOMETIMES THAT TAKES A LONG TIME.



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



CHAPTER 4:
BEING A CARER

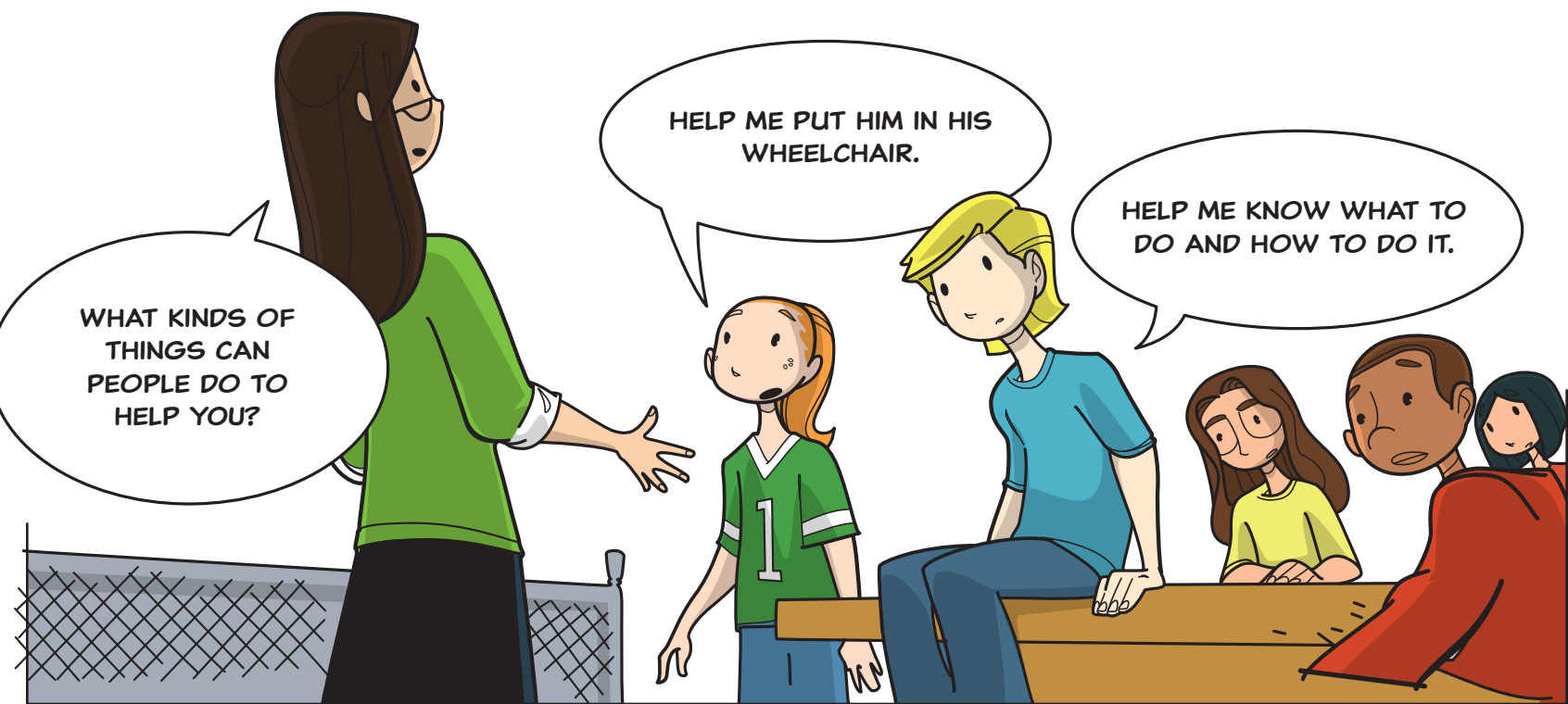
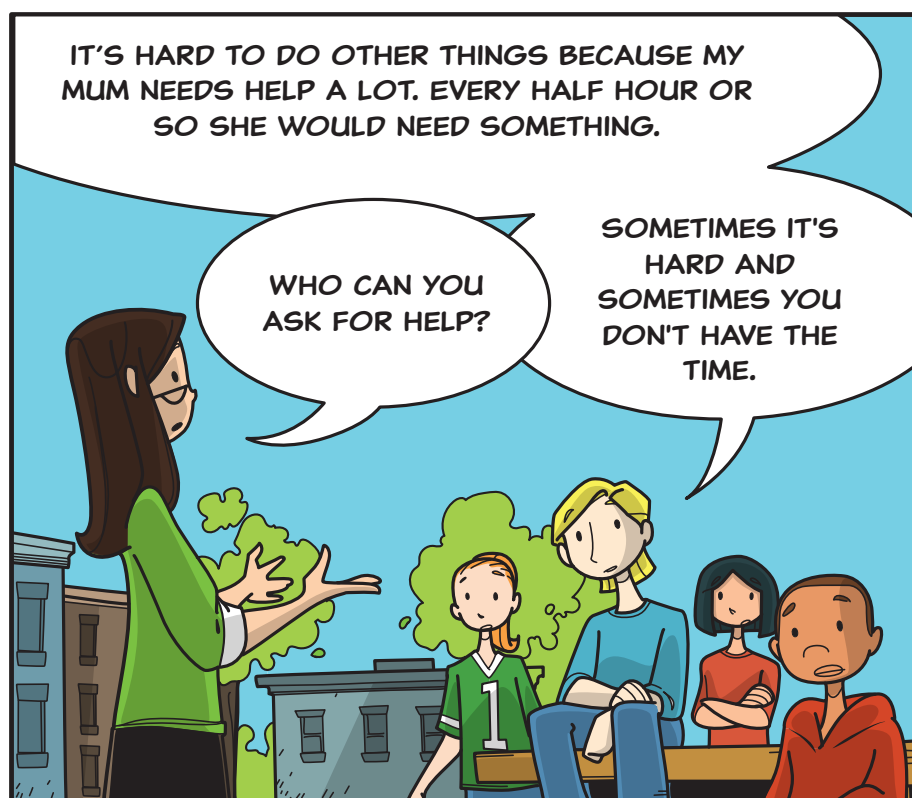
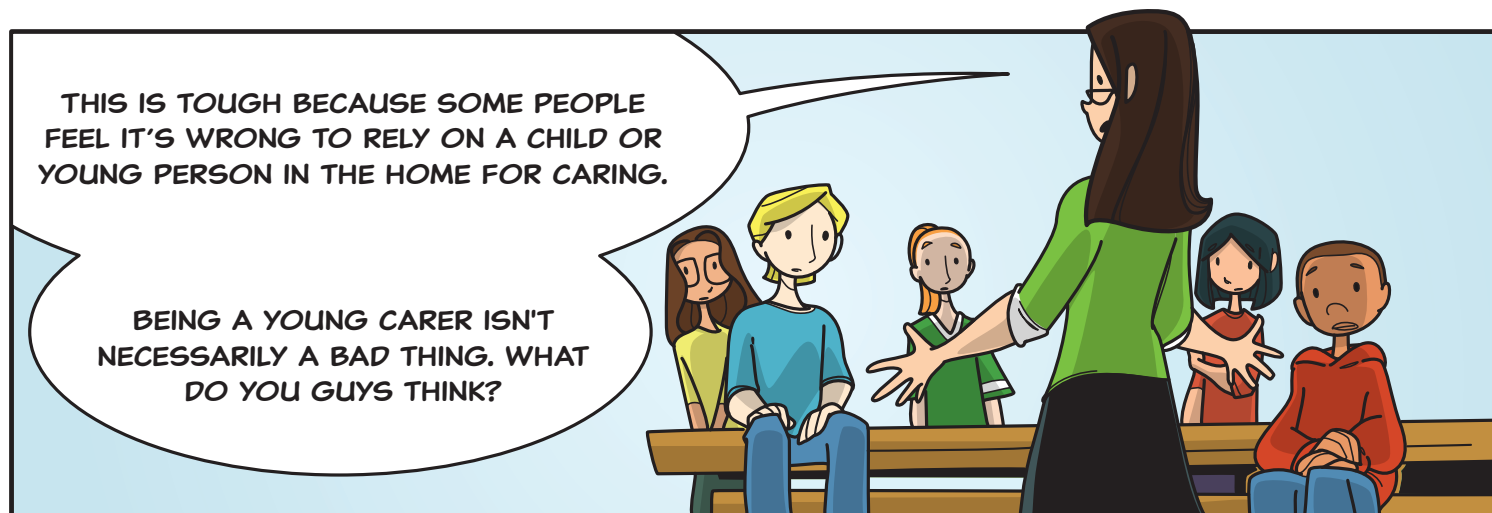


OK, LET ME BACK UP... TEACHERS AND RESEARCHERS USE THE TERM "CARER" TO DESCRIBE SOMEONE WHO DOES THINGS TO HELP, OR TAKE CARE OF, ANOTHER PERSON.

IN THIS CASE, IT'S KIDS LIKE YOU WHO HELP TAKE CARE OF A FAMILY MEMBER WITH MND. IN FACT, WE ASKED KIDS IF THEY SAW THEMSELVES AS A CARER. 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 CARER. IT'S UP TO YOU!





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

YES, BRIAN?

I DROPPED MY MUM. 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.

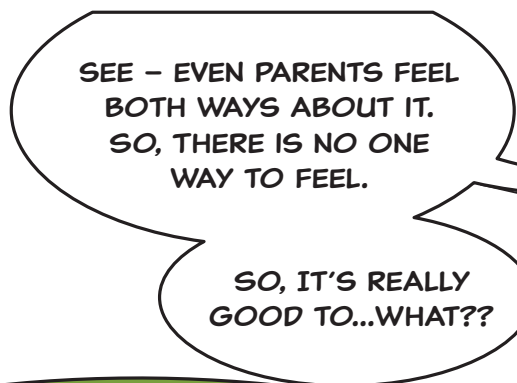
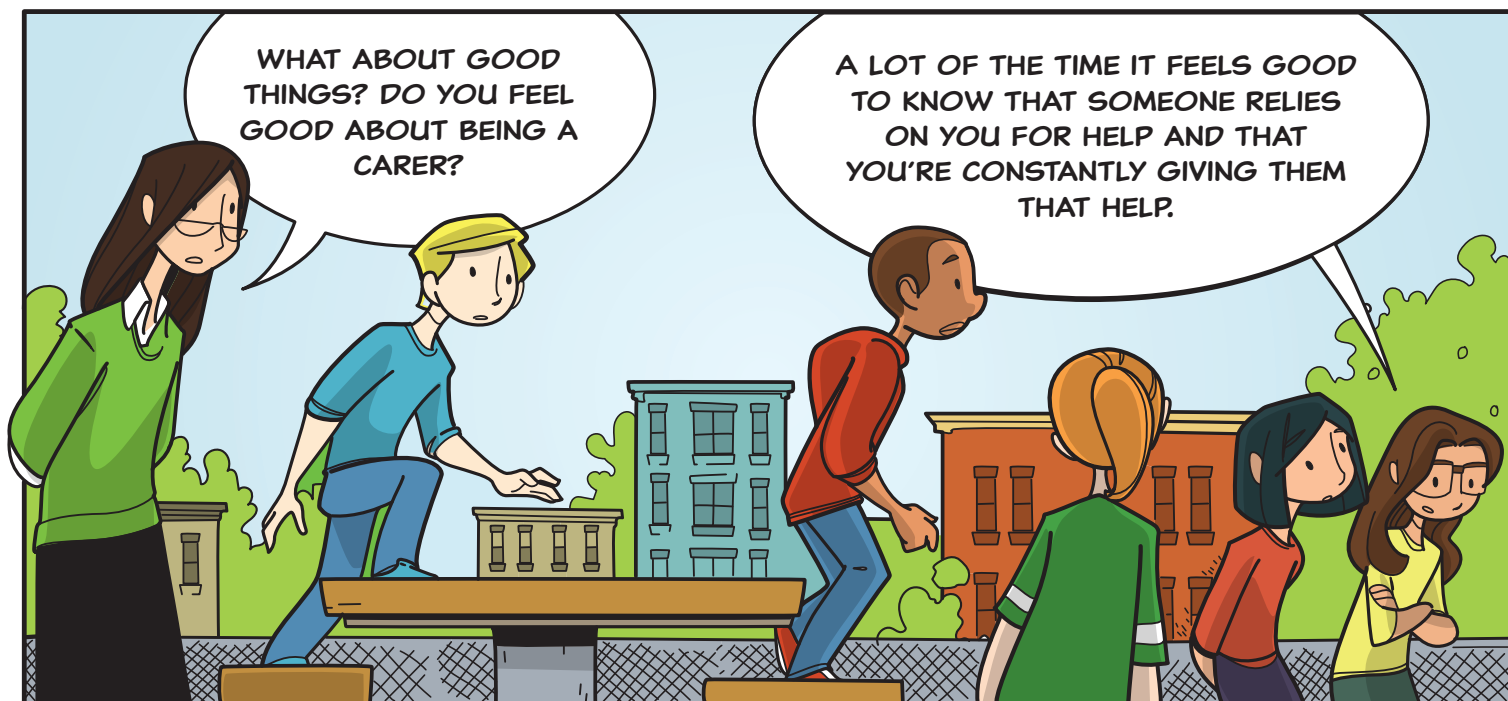
WHO CAN WE ASK TO HELP US KNOW WHAT TO DO?

MY MUM.

THE SOCIAL WORKER.

THE DOCTOR.

YES! GREAT IDEAS. BEING A CARER IS TOUGH. SO ALWAYS ASK FOR HELP. AND DON'T FORGET ABOUT MND SCOTLAND.



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 MUM, 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 MND. 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?

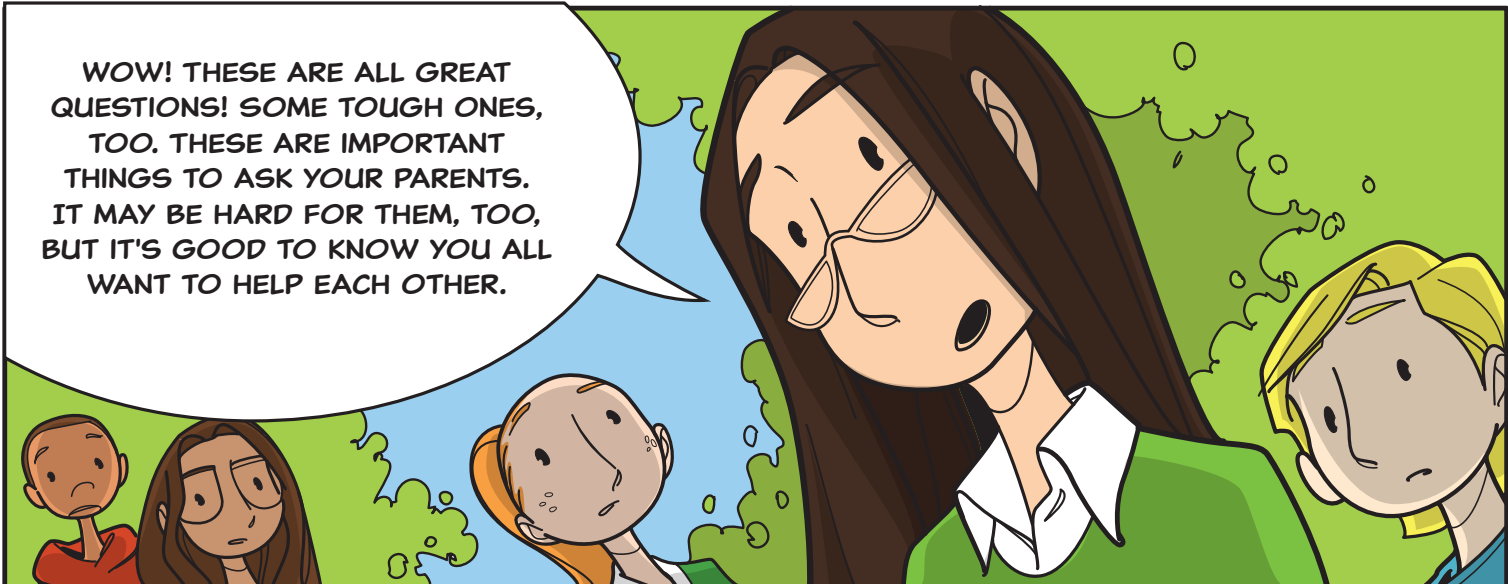
WILL I BE THERE WHEN HE DIES?

WHAT WILL THE SERVICES OR FUNERAL LOOK LIKE?

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 MUM 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 MND HAS CHANGED?

WHAT ABOUT FEELING LIKE YOU HAVE "LOST" A BEST FRIEND OR PARENT 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 MUM 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 MUM.

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?

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 SOME-
ONE 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 STOPPING POINT. 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 MND MEETING
NEXT WEEK?

WHAT IS YOUR
PHONE NUMBER?

I'M BRIAN, WHAT
IS YOUR NAME?

MND SCOTLAND IS 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. -
[HTTPS://MNDSCOTLAND.ORG.UK/](https://mndscotland.org.uk/)