



National Healthcare
Communication
Programme

End-of-Life Conversations Guiding Parents to Prepare Children/Young People when Someone Close is Dying



Making conversations easier

“

As difficult as it can be at times,
and as horrendous as the truth
may be, children want, need,
and deserve the truth.

(Schuurman 2003).

INTRODUCTION



I DON'T KNOW HOW TO TALK TO AISLING ABOUT ANY OF THIS.



A LOT OF PARENTS FEEL THAT WAY.



I'M FRIGHTENED I'LL SAY THE WRONG THING. OR MAKE IT WORSE.



WE CAN THINK IT THROUGH TOGETHER.

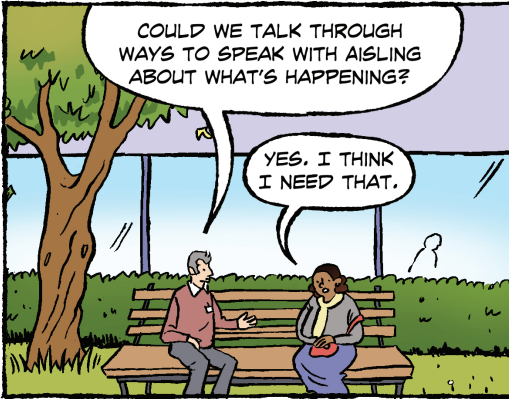


IF YOU'RE GOING TO HELP MY MUM FIND THE WORDS... COME A LITTLE CLOSER.

THERE ARE THINGS CHILDREN KNOW WITHOUT BEING TOLD.



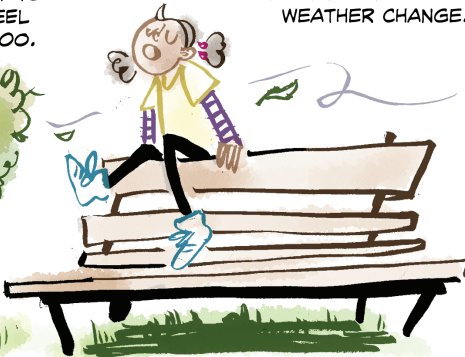
WHY THIS MATTERS



THE TRUTH CAN HURT. BUT BEING LEFT TO GUESS CAN FEEL FRIGHTENING TOO.

WHEN GROWN-UPS GO QUIET, CHILDREN STILL FEEL THE WEATHER CHANGE.

WE JUST HAVE TO STAND IN IT ON OUR OWN.

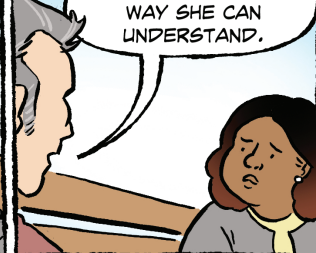


STARTING THE CONVERSATION

MY NAME IS PETER.
I'M ONE OF THE TEAM LOOKING AFTER KIERAN,
AND PART OF MY ROLE IS TO HELP FAMILIES
THROUGH CONVERSATIONS LIKE THIS.



WE CAN THINK TOGETHER
ABOUT WHAT AISLING MAY
ALREADY HAVE NOTICED,
WHAT SHE MAY NEED TO
KNOW NOW, AND HOW TO
EXPLAIN THINGS IN A
WAY SHE CAN
UNDERSTAND.



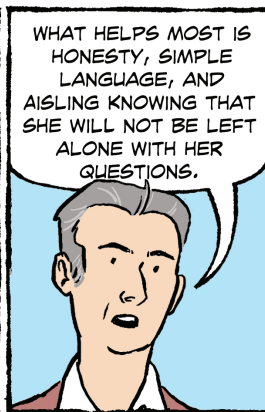
I KEEP THINKING
I NEED TO GET IT
EXACTLY RIGHT.



YOU DO NOT NEED
PERFECT WORDS.



WHAT HELPS MOST IS
HONESTY, SIMPLE
LANGUAGE, AND
AISLING KNOWING THAT
SHE WILL NOT BE LEFT
ALONE WITH HER
QUESTIONS.



WE USUALLY KNOW
SOMETHING IS CHANGING,
EVEN BEFORE ANYONE
EXPLAINS IT.



WHAT HELPS IS WHEN
THE TRUTH COMES
WITH SOMEONE
WILLING TO STAY.

BEFORE WE THINK ABOUT THE
WORDS THEMSELVES, IT MAY
HELP IF I FIRST MAKE SURE
I UNDERSTAND THE
SITUATION CLEARLY, AND
WHAT SUPPORT WOULD BE
MOST USEFUL FOR YOU.



BEFORE YOU HELP A
PARENT TALK TO A
CHILD LIKE ME...

MAKE A LITTLE
ROOM INSIDE
YOURSELF FIRST.



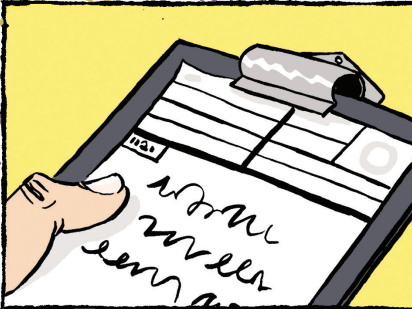
PREPARE YOURSELF



A CALM, PROFESSIONAL
DEMEANOUR MATTERS.



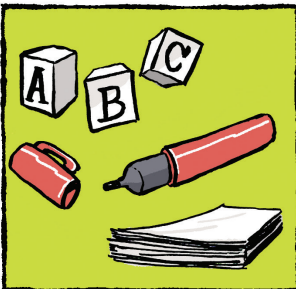
TAKE A MOMENT TO
STEADY YOURSELF.



BE CLEAR ABOUT THE CLINICAL
SITUATION, THE FAMILY CONTEXT,
AND WHAT THE CHILD MAY HAVE
ALREADY BEEN TOLD.



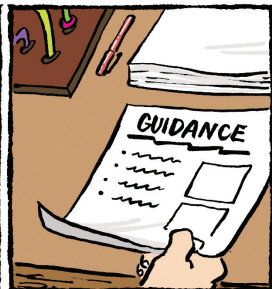
CHOOSE A PRIVATE PLACE
WHERE THE PARENT/CAREGIVER
CAN SIT COMFORTABLY.



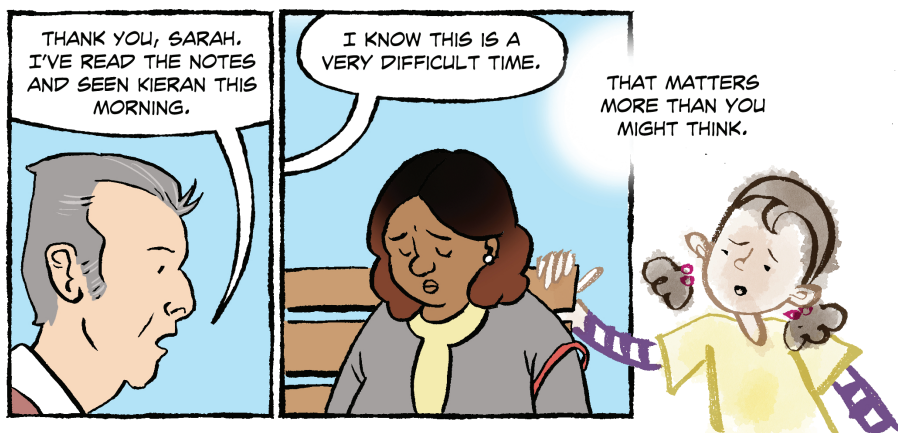
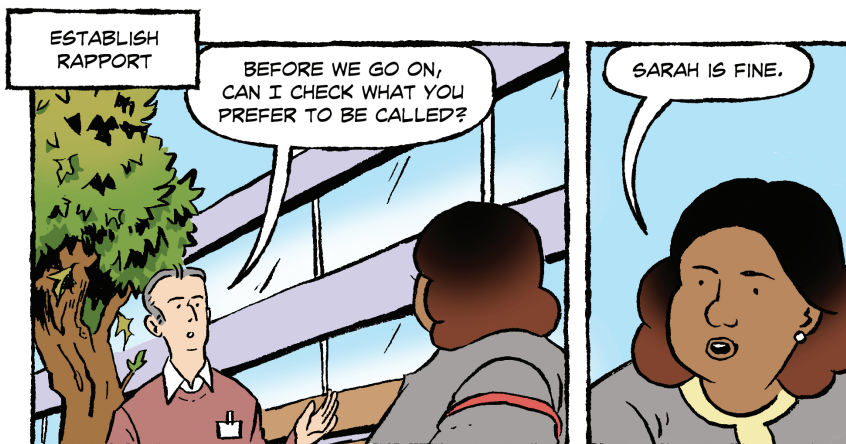
IF POSSIBLE, HAVE SIMPLE
MATERIALS READY THAT
PARENTS CAN LATER USE
WITH THEIR CHILD.



SOME WORDS NEED
A LITTLE TIME AND
SPACE AROUND
THEM.



HAVE A SIMPLE HANDOUT
READY FOR LATER
REFERENCE, IF HELPFUL.



IF YOU'RE HELPING
MY PARENT,

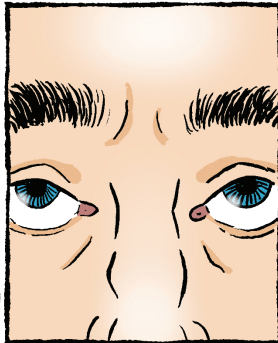
LET WARMTH
COME BEFORE
INFORMATION.



NON-VERBALS



AN OPEN POSTURE

A FACE THAT SHOWS
CARE AND CALMGENTLE, APPROPRIATE
EYE CONTACTSUPPORT THAT DOES
NOT CROWDA WARM TONE AND
UNHURRIED PACEYOUR BODY SPEAKS
BEFORE YOUR WORDS DO.IF YOU CAN STAY STEADY BESIDE THE HARD BIT,
MY PARENT MAY FEEL THEY CAN STAY THERE TOO.

SOMETIMES CALM IS
WHAT MAKES HARD
WORDS POSSIBLE.



ASSESS UNDERSTANDING

JUST SO I KNOW WHERE TO BEGIN, CAN YOU TELL ME WHAT YOU UNDERSTAND ABOUT WHY KIERAN IS SO UNWELL?



WHAT HAVE YOU EXPLAINED TO AISLING SO FAR?

WHAT WORDS HAVE YOU BEEN USING WITH HER?



WHAT DO YOU THINK SHE UNDERSTANDS ABOUT WHAT IS GOING ON?



I'VE TOLD HER THAT HER DAD IS VERY SICK. I DON'T THINK I'VE SAID MORE THAN THAT.



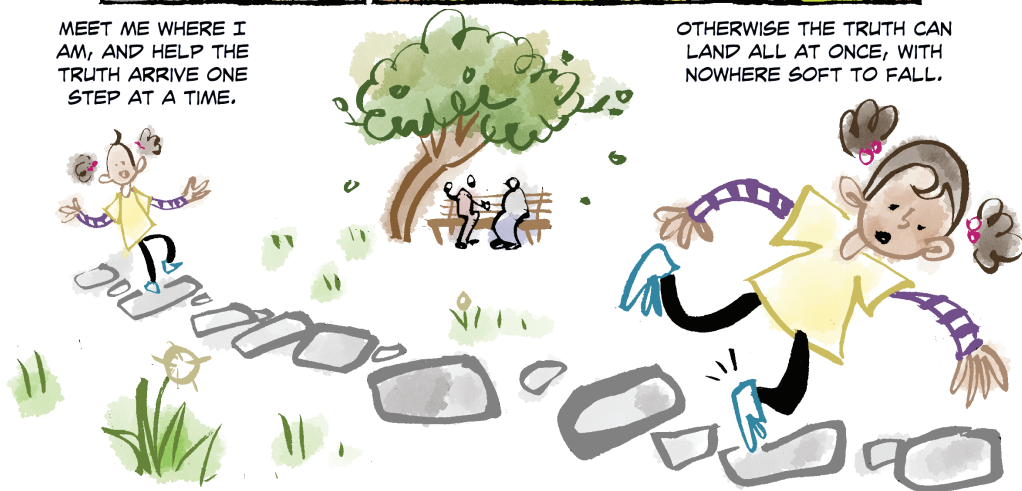
SHE KNOWS IT'S CANCER. I DON'T THINK SHE KNOWS THAT KIERAN MIGHT DIE.

THANK YOU. THAT HELPS ME UNDERSTAND YOUR STARTING POINT.



MEET ME WHERE I AM, AND HELP THE TRUTH ARRIVE ONE STEP AT A TIME.

OTHERWISE THE TRUTH CAN LAND ALL AT ONCE, WITH NOWHERE SOFT TO FALL.



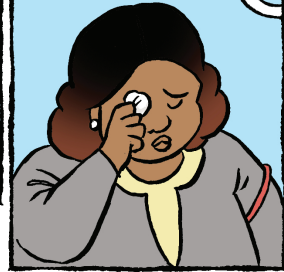
EMPATHY & SILENCE

I CAN'T EVEN SAY THE WORD OUT LOUD.



PAUSE. LET EMOTION BE PRESENT.

I CAN HEAR THIS IS REALLY HARD TO TALK ABOUT.



IT SOUNDS LIKE YOU'VE BEEN CARRYING A LOT.



~~DON'T WORRY, SHE'LL BE FINE. YOU'LL KNOW WHAT TO SAY.~~



DON'T HURRY PAST THE SAD PART AS IF IT WERE THE WRONG ROAD.



SOMETIMES THE SAD PART NEEDS A LITTLE ROOM TO BE THERE.

IF YOU RUSH TOO QUICKLY TOWARD COMFORT, I MAY WONDER IF MY SADNESS IS ALLOWED TO STAY IN THE ROOM.



PROVIDING INFORMATION

I'LL GIVE THIS IN SMALL
PIECES, AND WE CAN
STOP AT ANY POINT.



SOME PARENTS WANT HELP
FINDING THE WORDS.

OTHERS WANT TO THINK FIRST
ABOUT WHAT THEIR CHILD
MAY NOTICE OR ASK.



SOME PEOPLE WANT TO KNOW WHAT
MIGHT HAPPEN NEXT, OR WHAT IT CAN BE
LIKE WHEN SOMEONE IS DYING, SO THEY
CAN PREPARE THEIR CHILD.

WOULD THAT BE HELPFUL
TO TALK ABOUT?

YES... I THINK
I NEED THAT.



WHAT ARE YOU MOST
WORRIED AISLING MIGHT
SEE OR MISUNDERSTAND?

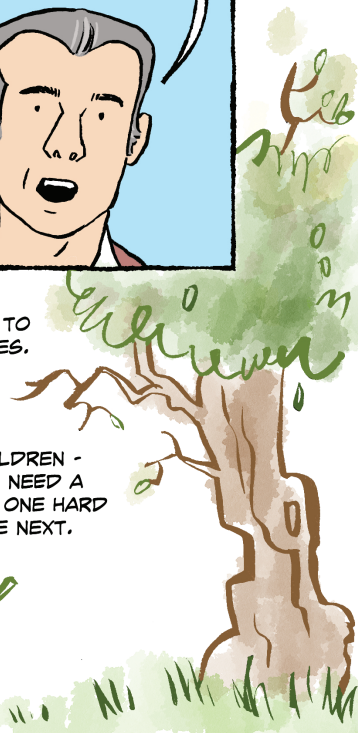


THAT SHE'LL THINK KIERAN'S
GETTING BETTER IF HE HAS
A GOOD DAY.
OR THAT SHE'S DONE
SOMETHING WRONG.



BIG TRUTHS ARE EASIER TO
CARRY IN SMALLER PIECES.

SOMETIMES CHILDREN -
AND PARENTS - NEED A
BREATH BETWEEN ONE HARD
TRUTH AND THE NEXT.



CLEAR LANGUAGE
ABOUT DYING

IT USUALLY HELPS
CHILDREN IF THEY ARE
TOLD WHAT IS HAPPENING
CLEARLY AND HONESTLY.



YOU DO NOT HAVE TO
GET EVERY WORD
EXACTLY RIGHT.

WHAT MATTERS MOST
IS BEING CALM, CLEAR
AND TRUTHFUL.



IF YOU CAN, CHOOSE A TIME
WHEN THERE AREN'T LOTS
OF OTHER PRESSURES.

SOMETIMES TALKING SIDE
BY SIDE - WALKING,
DRAWING, TRAVELLING - IS
EASIER THAN FACE TO FACE.



START BY FINDING OUT
WHAT AISLING ALREADY
KNOWS OR THINKS.

IF SHE SAYS SOMETHING THAT
DOESN'T MATCH WHAT YOU
KNOW, LET HER FINISH BEFORE
YOU GENTLY CORRECT IT.



SIMPLE RESPONSES LIKE "MMM-HMM,"
"I GET IT," OR "THANK YOU FOR
TELLING ME THAT" CAN HELP HER KEEP
GOING.



WHEN YOU LET ME FINISH, IT
FEELS LIKE MY THOUGHTS
HAVE SOMEWHERE TO LAND.

FINDING THE WORDS

YOU CAN USE THE WORDS AISLING USES, AND GENTLY CHECK WHAT SHE UNDERSTANDS.

IT HELPS TO AVOID CONFUSING PHRASES LIKE 'GONE TO SLEEP,' UNLESS YOU EXPLAIN EXACTLY WHAT YOU MEAN.

YOU MIGHT SAY:

YOUR DAD IS VERY ILL, AND THE DOCTORS DON'T HAVE ANY MEDICINES THAT CAN MAKE HIM BETTER NOW.

THEN YOU MIGHT ADD:
HIS BODY IS SLOWING DOWN. HE MAY NOT BE ABLE TO TALK OR WALK, BUT HE CAN STILL HEAR YOU.

AND WHEN YOU NEED TO BE CLEARER STILL:
WHEN SOMEONE'S BODY STOPS WORKING AND CANNOT START AGAIN, THAT IS CALLED DYING.

CLEAR WORDS CAN BE HARD TO HEAR.

BUT CONFUSION CAN BE HARDER TO CARRY.

WHAT WORRIES YOU MOST RIGHT NOW - FOR YOU, AND FOR AISLING?

THAT SHE'LL BE FRIGHTENED. AND THAT I WON'T KNOW HOW TO ANSWER HER.



SHARED PLANNING

IT CAN HELP TO ASK QUESTIONS THAT GENTLY INVITE HER TO SPEAK, IN HER OWN TIME.



YOU COULD TRY THINGS LIKE:

I WONDER IF...

WHEN YOU'RE READY...

WOULD IT BE ALRIGHT TO...

IF YOU'D LIKE, COULD YOU TELL ME...?

I WONDER IF YOU'VE BEEN THINKING ABOUT HOW DAD'S DOING?



WHEN YOU'RE READY, YOU CAN ASK ME ANYTHING.



IF NEEDED, YOU CAN BE MORE DIRECT:

I KNOW IT'S REALLY HARD, AND I NEED TO TALK WITH YOU ABOUT WHAT IS HAPPENING TO DAD.



WE CAN ALSO THINK TOGETHER ABOUT WHO COULD BE THERE. WHETHER YOU WANT ANOTHER TRUSTED ADULT NEARBY. WHETHER IT WOULD HELP TO PRACTISE THE FIRST FEW SENTENCES.



I THINK I WOULD LIKE TO PRACTISE THEM.

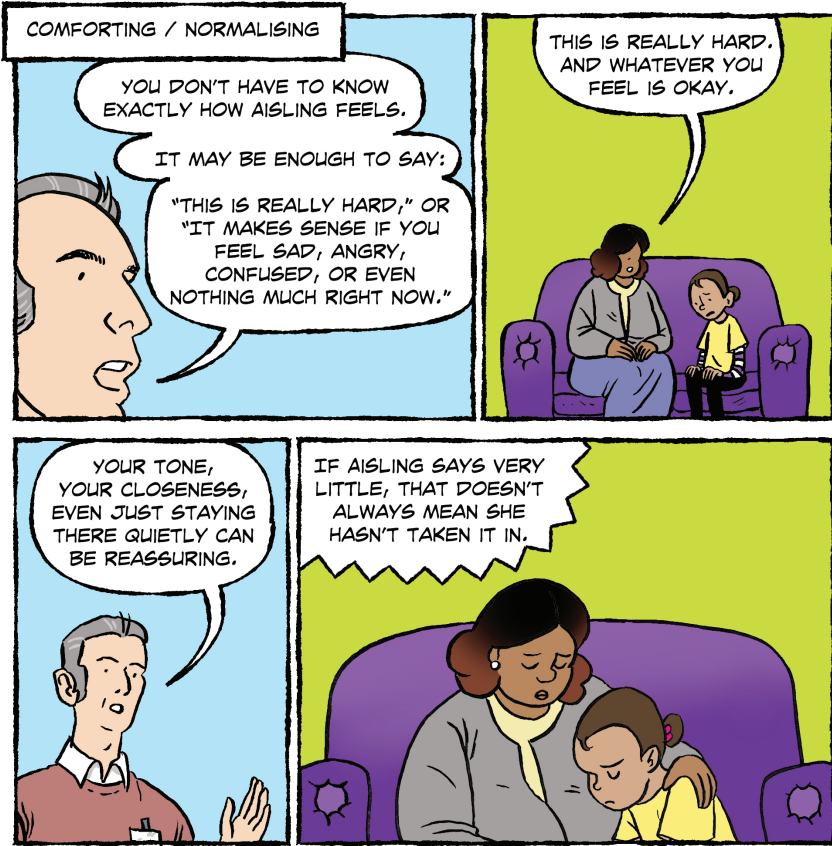
WE CAN DO THAT.



I DON'T ALWAYS NEED PERFECT WORDS.

I NEED TO FEEL YOU CAN STAY WITH ME WHILE MY FEELINGS CATCH UP.





SOMETIMES WE GO
QUIET BECAUSE
SOME FEELINGS
TAKE LONGER TO
PUT INTO WORDS.

SOMETIMES PRACTICAL
QUESTIONS ARE JUST THE
SAFEST DOOR INTO
SOMETHING FRIGHTENING.



THINGS CHILDREN
MAY THINK & SAY

CHILDREN CAN
REACT IN LOTS OF
DIFFERENT WAYS.



SOME SEEM CALM.

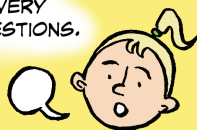


SOME GET ANGRY.

SOME GET UPSET LATER.



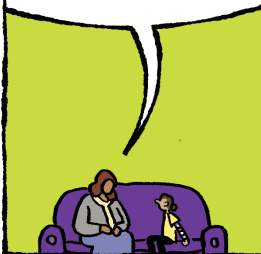
SOME ASK VERY
PRACTICAL QUESTIONS.



SOME CHILDREN
QUIETLY WORRY THEY
CAUSED THE ILLNESS.



IF YOU'VE EVER
WONDERED THAT,
I WANT YOU TO KNOW
THERE'S NOTHING YOU
DID OR DIDN'T DO THAT
MADE THIS HAPPEN.



SHE MAY ASK THINGS
LIKE, 'WHEN WILL DAD
DIE?'; 'WILL I STILL
LIVE HERE?' OR 'WILL
HE STILL BE HERE ON
MY BIRTHDAY?'



WHAT IF I DON'T
KNOW THE ANSWER?

THEN IT'S OKAY TO SAY THAT.

YOU CAN BE HONEST
ABOUT UNCERTAINTY, AND
COME BACK WITH MORE
INFORMATION IF YOU CAN.



I DON'T NEED
YOU TO KNOW
EVERYTHING AT
ONCE.

I NEED TO KNOW
YOU WON'T LEAVE
ME ALONE WITH
THE QUESTION.



NEXT STEPS & CLOSING

IF AISLING ASKS WHEN KIERAN WILL DIE, YOU MIGHT SAY:

THAT'S A REALLY IMPORTANT QUESTION. I WISH I COULD TELL YOU FOR SURE. WE CAN'T KNOW THE EXACT TIMING.



IF KIERAN SEEMS A LITTLE BETTER ONE DAY, YOU CAN EXPLAIN THAT PEOPLE WHO ARE VERY ILL SOMETIMES HAVE STRONGER DAYS AND WEAKER DAYS. IT DOES NOT NECESSARILY MEAN THE ILLNESS HAS GONE AWAY.



IF WE ARE THINKING IN TERMS OF DAYS RATHER THAN WEEKS, WE MIGHT TALK TOGETHER ABOUT HOW AND WHEN TO TALK WITH AISLING, AND HOW TO HELP HER SPEND TIME WITH HER DAD.



THAT HELPS. IT MAKES IT FEEL A BIT LESS IMPOSSIBLE.



SO, I'VE GIVEN YOU QUITE A LOT OF ADVICE ON HOW TO TALK WITH AISLING.

WE DON'T EXPECT YOU TO REMEMBER ALL OF IT.



HERE'S A SHEET WITH THE MAIN POINTS.

IS THERE ANYTHING YOU WERE WONDERING ABOUT THAT I HAVEN'T TALKED ABOUT YET?



WHEN EVERYTHING FEELS TOO MUCH, IT HELPS IF THE WORDS CAN WAIT ON THE PAGE UNTIL THEY'RE READY TO BE PICKED UP.

WAS THERE ANYTHING I SAID THAT DIDN'T MAKE SENSE, OR THAT YOU'RE NOT SURE HOW TO EXPLAIN TO AISLING?



ONE CONVERSATION CAN OPEN THE DOOR.



IT HELPS TO KNOW THIS WILL NOT BE THE ONLY CONVERSATION.



STAFF SELF-CARE

I'LL WRITE DOWN WHAT WE DISCUSSED SO THE TEAM KNOWS WHAT WE'VE TALKED ABOUT. WE'LL KEEP YOU UPDATED IF ANYTHING CHANGES.



WE CAN CHECK IN AGAIN TOMORROW, AND YOU CAN ASK TO SPEAK WITH US SOONER IF YOU NEED TO.



IT CAN ALSO HELP TO LET SCHOOL, OR ANOTHER TRUSTED ADULT IN AISLING'S LIFE, KNOW WHAT IS HAPPENING SO THEY CAN SUPPORT HER TOO.



THIS IS VERY HARD ON YOU.

LOOKING AFTER YOURSELF - EVEN IN SMALL WAYS LIKE EATING, RESTING, OR GETTING SOME FRESH AIR - WILL ALSO HELP YOU SUPPORT AISLING.

I HADN'T REALLY THOUGHT ABOUT THAT.



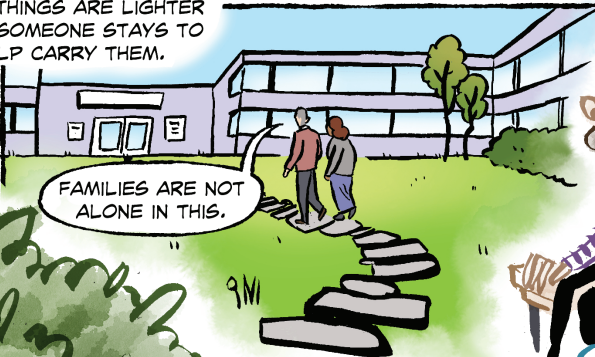
THESE CONVERSATIONS CAN BE EMOTIONALLY DEMANDING FOR STAFF TOO.



LEAN ON SUPERVISION, DEBRIEFING, AND TEAM SUPPORT. STEP OUT, BREATHE, GET SOME AIR, AND COME BACK WHEN YOU ARE READY.

HARD THINGS ARE LIGHTER WHEN SOMEONE STAYS TO HELP CARRY THEM.

FAMILIES ARE NOT ALONE IN THIS.



AND STAFF SHOULD NOT BE ALONE EITHER.





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