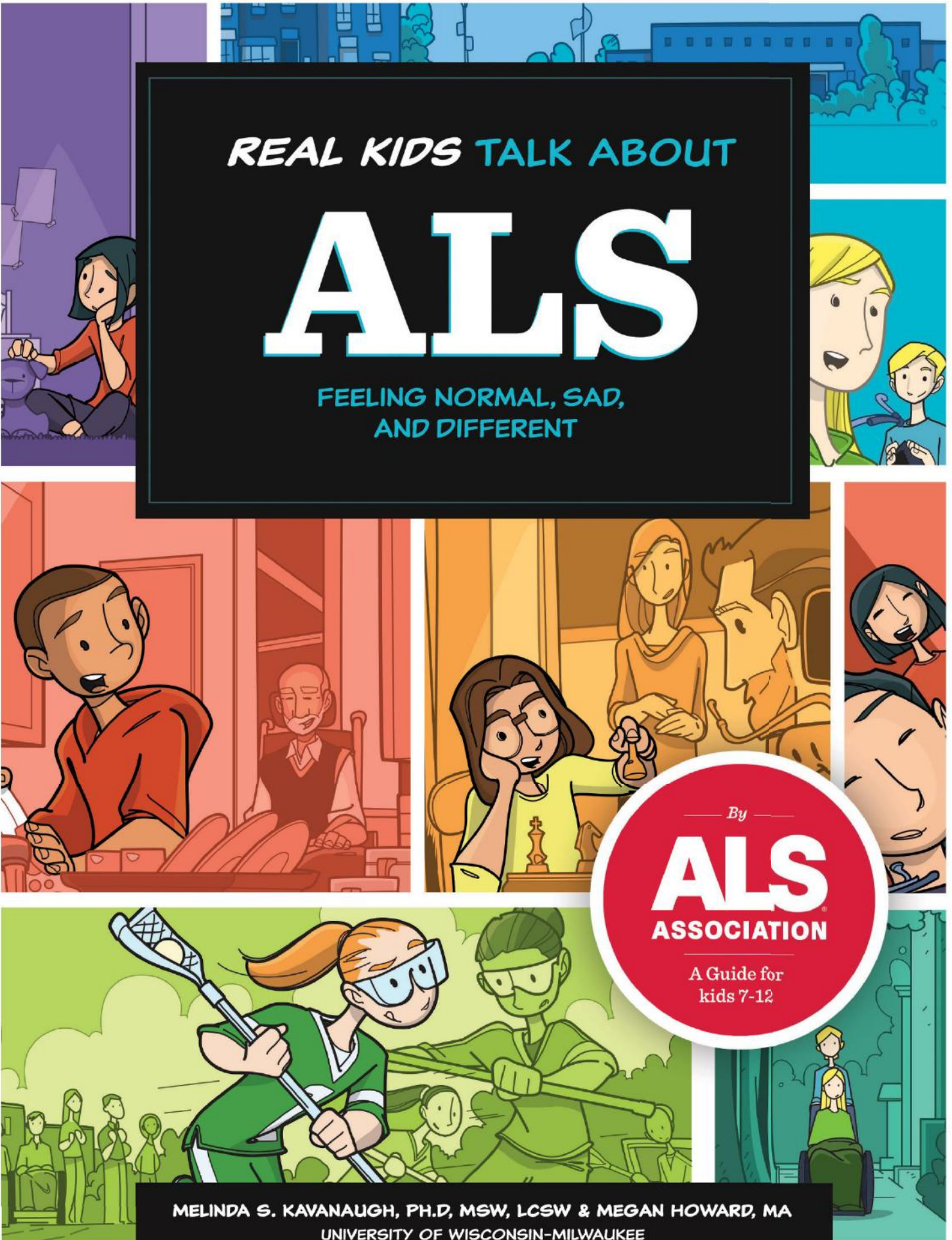


REAL KIDS TALK ABOUT

ALS

FEELING NORMAL, SAD,
AND DIFFERENT



By

ALS
ASSOCIATION

A Guide for
kids 7-12

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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**
Translated by **Lucy Magwaca and Sanele Mthembu**

Kungani sibhale le ncwadi?

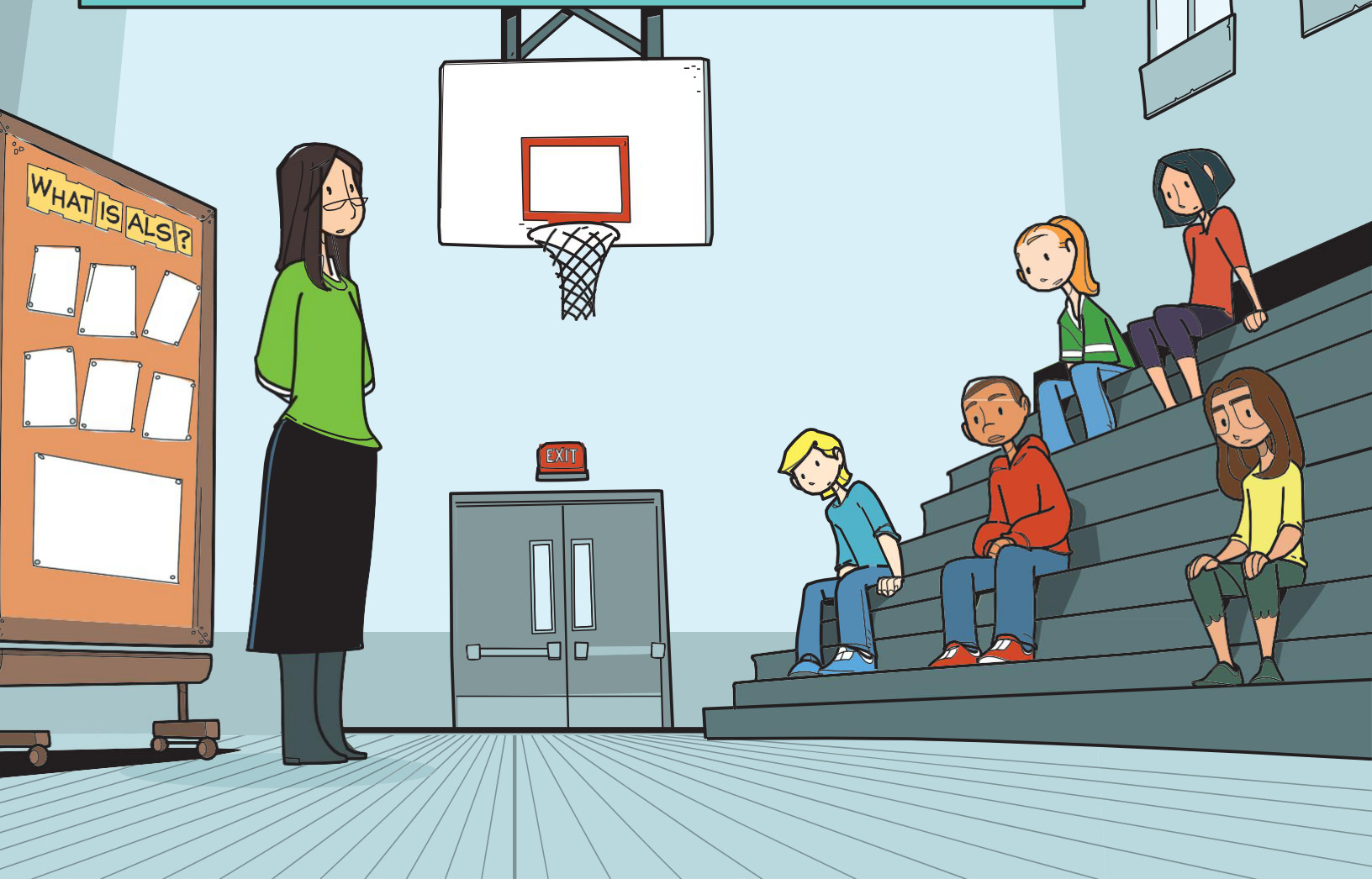
I-ALS ithinta wonke umuntu emndenini – kanye nezingane.

Alukho ulwazi oluningi olutholakalayo lokusiza izingane zibe nokuqondisisa ukuthi yini i-ALS, eyiphi indima oyidlalayo njengomnakekeli, nezindlela zokukhuluma ngalezi zinkinga.

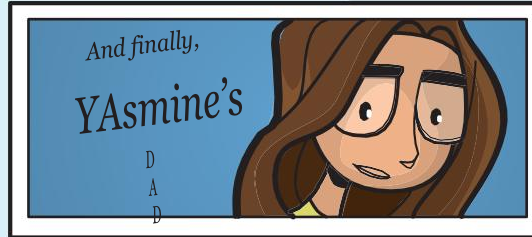
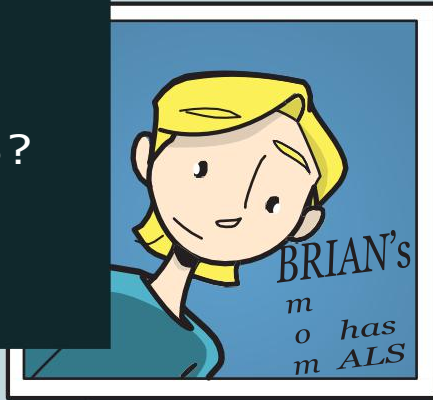
UDkt. Melinda Kavanaugh wenze ucwaningo olubanzi ngemindenini ephila nokuphazamiseka kwemisipha – nayo i-ALS. Ubuze abazali kanye nezingane ngezidingo zabo, ngolwazi lwabo nabangakwazi nge-ALS.

Zonke izitatimende zentsha ezikule ncwadi zithathwe ezinganeni eziphila nemindenini ehlaselwe yiALS okwangempela – njengawe.

Siyawathanda amanoveli wezithombe futhi siyethemba ukuthi nawe uzowathanda. Kwenza kubelula kakhulu ukukhuluma nge-ALS. Siyabonga kwimindenini ebe yinxenye yocwaningo lwe-ALS lukazwelonke lemindenini nentsha. nakuBella – okhulume ngendaba yakhe nobuciko bakhe ukuze lencwadi iphumelele.



Isahluko 1:
Iyini i-ALS?



Sanibonani nonke!

Kungaba nobunzima kweminye imindeni ukukhuluma nge-ALS.

Sifuna ukunisiza nibe nolwazi olungcono (olubanzi) nge-ALS futhi nithole izindlela zokukhuluma nemindeni yenu kanye nabangani benu ngayo.



Ihlasela izinyama zomzimba bese iyazibulala.

Yebo, Alison, uqinisile!

I-ALS yenzeka uma ama-nuerons eyeka ukukhuluma nenyama yomzimba wakho, njengoku nqamuka kotingo ungasezwa umuntu okhuluma naye. Uma lokhu kwenzeka, umuntu one-ALS uyehluleka ukusebenzisa izingalo zakhe ngoba izinyama zomzimba zisuke zingazi ukuthi zenzeni.

Umama wami uyehluleka ukunyakaza.

Uqinisile, Carrie. abantu abaningi abanayo iALS abanyakazi kodwa akuyena wonke umuntu onganyakazi futhi akwenzeki ngesikhathi uqala ukubanayo iyindida, angithi

I-ALS ibukeka ihlukile kubantu abahlukile. Wonke umuntu kulezithombe unayo i-ALS..

A I-ALS idala ukuphelelwa amandla nokuphela kwezinyama zomzimba izizimele, okuchaza ukuthi izinyama zomzimba esizisebenzisayo ukuze sikwazi ukunyakaza, ukugwinya nokuphefumula ziba nokuphazamiseka.

Yebo, Brian?

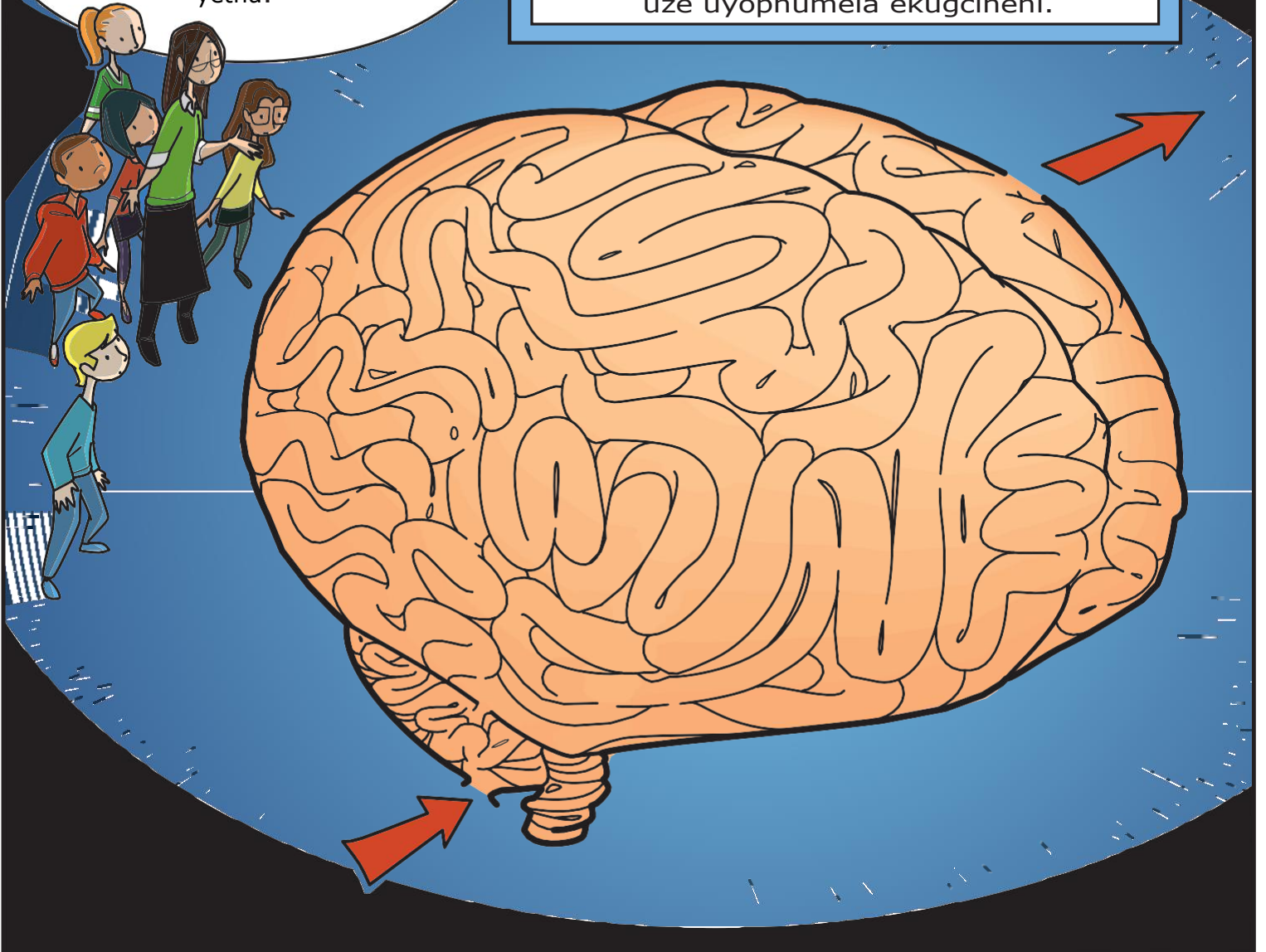
Bengicabanga ukuthi amantombazane kuphela abanayo.

Eqinisweni, wonke umuntu angabanayo i-ALS. Kaningi yenzeka kubantu abadala. iALS ingenzeka kubantu besilisa nakubantu nabesifazane.



Inqondo yinto emangaza kakhulu. Yindawo elawula indlela esikhuluma ngayo, esihamba ngayo nemicabango yethu.

Sebenzisa le *maze* ukuhamba enqondweni. Bona ukuthi ungakhona ukuhamba kuyona uze uyophumela ekugcineni.



Manje, umqondo, yi-ALS, ama - neurons izihloko eziningi ezibalulekile. Ingabe ukhona onombuzo?







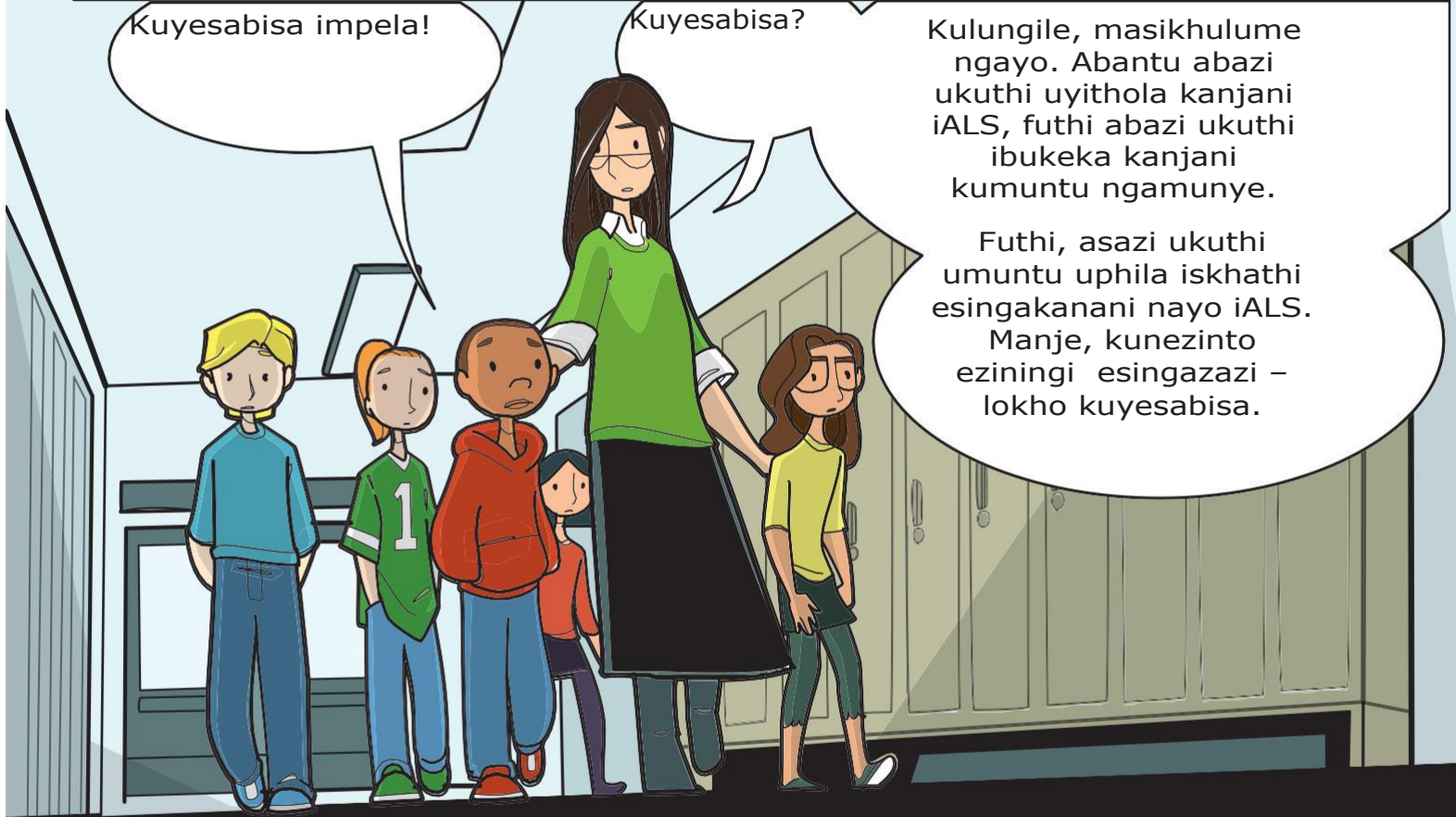
Ukwenzela le zingane ezingekho nathi, kunjani ukuba nomzala noma Ilunga lomndeneni one-ALS?

Kuyesabisa impela!

Kuyesabisa?

Kulungile, masikhulume ngayo. Abantu abazi ukuthi uyithola kanjani iALS, futhi abazi ukuthi ibukeka kanjani kumuntu ngamunye.

Futhi, asazi ukuthi umuntu uphila iskhathi esingakanani nayo iALS. Manje, kunezinto eziningi esingazazi – lokho kuyesabisa.



Ukhathazekile futhi awazi uzokhuluma nobani. Umasikhuluma awuwedwa. Intsha ikhuluma ngobuntu nokwesaba kwethu, siyasizana ukuze sizizwe singcono.

Ngifuna ukunitshela ngoBella.



Isahluko 2: Ukukhuluma nge-ALS



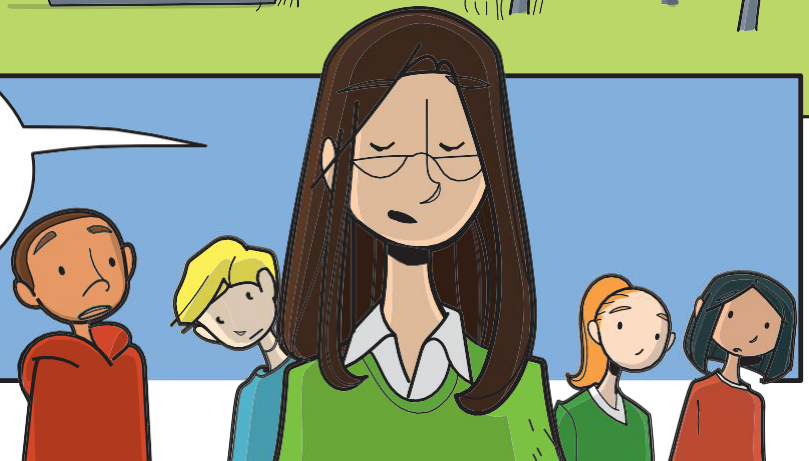
UBella uneminyaka engu-11. Ubaba wakhe wayene-ALS. Ngithi wayene-ALS ngoba washona ngonyaka odlule. Ubaba wakhe akazange abe ne-ALS isikhathi eside, ngakho-ke kwaba nzima ukuqondisisa ukuthi kwenzakalani.

UBella wayazi ukuthi kukhona okushaya amanzi ngesikhathi ubaba wakhe ewa kakhulu. Kanti nezwi lakhe lakhe laqala ukuzwakala ngendlela engajwayelekile. UBella wayezwana kakhulu nobaba wakhe. Ubaba wakhe wayemdlalisa ngamancoko, nokumhlelisa. Ngakho-ke UBella waqala ukwesaba ukuthi kungathi kukhona okubi okwenzekalayo kubaba wakhe.

Umndeni kaBella wawungafuni ukukhuluma kakhulu ngokwakwenzeka ngoba ungafuni ukuthi akhathazeke. Baya kodokotela abaningi ekugcineni bamthola udokotela owaveza ukuthi ubaba kaBella une-ALS. UBella uthi ukuthola ukuthi ubaba wakhe une-ALS kwaba nzima kuyena ngoba uyashesha ukukhathazeka, futhi uyesaba ukukhukuma nomndeni wakhe ngezinto eziningi, nange-ALS. Ngokuhamba kwesikhathi, kwaba lula ukuthi akwazi ukukhuluma nge-ALS.



Okwenzeka kuBella kujwayelekile. Kwesinye isikhathi imindeni ayikhulumi ngoba bengafuni ukuphathana kabi. Kungenzeka ukuthi unembuzo eminingi, njengoBella.



Kulungile ukubuza abazali bakho, noma amalunga omndeni nge-ALS. Futhi kungenzeka ukuthi Basabe ngaphezu kwakho!

Ungasabi ukubuza imibuzo. Okuhle kakhulu esungakwenza ngukuthi, sikhulume ngayo.



Mina ngikhulume nobaba kodwa uthe akazi kahle, uzobuza komunye.



Kulungile Brian. Abantu abadala abahlezi benezi mpendulo. Kodwa kukhona abazi kangcono, njengodokotela, nabantu abangamalunga esosiyeshini ye-ALS.



Haibo yimani, kuyathusa yini ukuphila ne-ALS?



Cha bo! Akuhlukile nokuphila nomuntu ongenayo. Akumshintshi umuntu, umehluko ngukuthi isifo somzimba nje esimphethe. Kunezinto ezingaphezulu okuzomele uzenze ukusiza. Kodwa kulungile ngoba uyamthanda lowo muntu one-ALS..



Uphendule kahle Tristan!





Sithe ukukhuluma nomndeni kubalulekile. Konje singakhuluma yini nabanye abantu? Ukhona kinina oke wakhuluma nabanye abantu nge-ALS?

Mina ngikhulume nosonhlalakahle wesikole.

Mina ngikhulume no-anti wami

Mina ngikhulume nomngane wami omkhulu



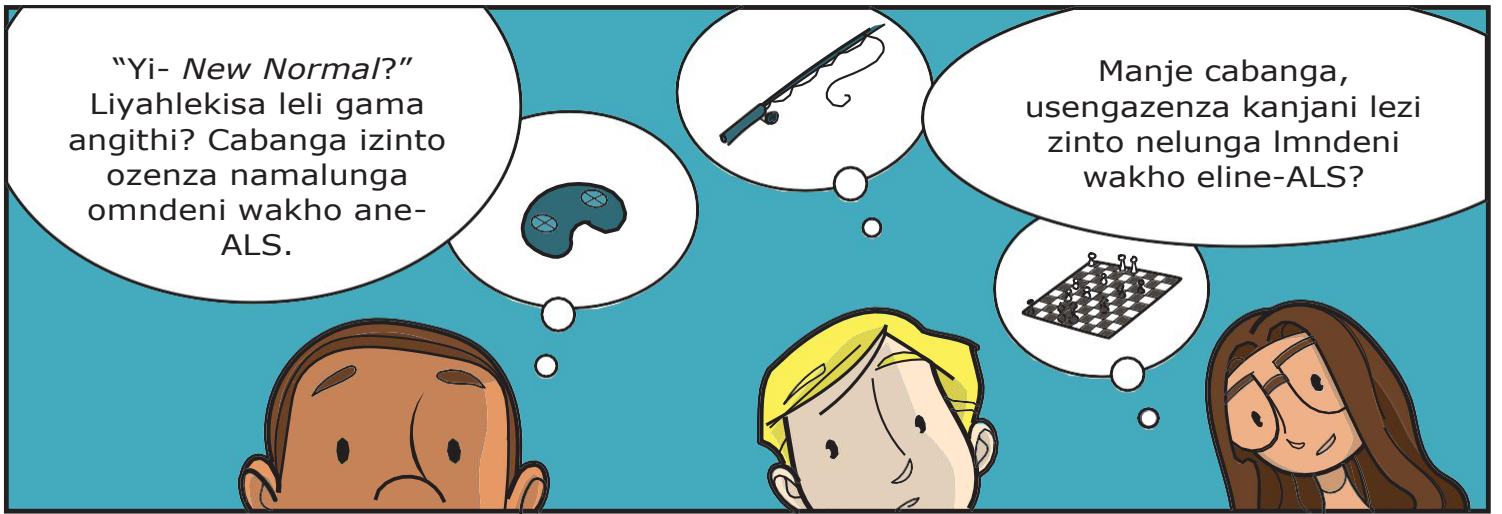
Mina angikhulumanga namuntu ngoba bengingafuni ukuthi ubaba aphaatheke kabi ngokukhuluma engazi.

Lihle iphuzu lakho Yasmine. Kukhombisa ukuthi umthanda kangakanani ubaba wakho. Kwenza umqondo ukuthi awufuni ukumzisa ubuhlungu. Kodwa ukukhuluma nomuntu ngemizwa Yakho ngeke kumzwise ubuhlungu. Kulungule ukhulume nomuntu omethembayo ngemizwa yakho. Kodwa futhi kubalulekile ukuthi nikhuluma ngani.

Akunankinga ukuthi uphatheke kabi ngokushintsha kwezinto nokukhuluma ngokuthi uzizwa njani.







"Yi- *New Normal*?"
Liyahlekisa leli gama
angithi? Cabanga izinto
ozenza namalunga
omndeni wakho ane-
ALS.

Manje cabanga,
usengazenza kanjani lezi
zinto nelunga Imndeni
wakho eline-ALS?



Eh! Mina
ngijwayele
ukugijima nobaba,
kodwa manje ukwi-

Yebo
Ngempela!

Mhlambe
Ningaqhudelan
a ngezihlalo?



Jmkhulu wami
wayengumlimi, mina
ngimsiza, kodwa manje
akakwazi ukusebenzisa
mishini.
Mhlambe
ngingamcela ukuthi
angitshale
ukuthi ngenzeni
noma angitshale
ngesikhathi sakhe
esangumfana

Imibono emihle yonke le.
Kwesinye isikhathi kufanele
sicabange izinto ngendlela
eyahlukile noma "nge-new
normal"

Lolushintsho
alukwenzi omunye
umuntu owehlukile;
umndeni wakho
usawumndeni wakho.
Futhi lokho kulungile.



Sise lapho nje, lokhu kusiya kwesinye isihloko
esilandelayo....

Isahluko 3: Abangani nesikole

Ukubeyela esikoleni noma ukuqala Isikole esisha kumnandi, kuyesabisa futhi kuyadida. Uhlangana nabangane abasha okokuqala noma ubone abangane bakudala.

Akunankinga ukubona abafundi ubacabengele ukuthi bangabantu abanjani. Injani imindeneni yabo? Ikakhulukazi uma emndenini wakho kukhona osanda kuthola ukuthi une-ALS

Tristan, ngiyazi ukuthi uqale Isikole esisha. Kunjani esikoleni esisha?

Ngithe ngifika esikoleni esisha, kwathi asiye phambili siyokhuluma ngemndeneni yethu... bengisaba ngoba ngimusha. Kodwa eh, ngitshele uthisha ngomkhulu wami. Emva kwalokho abangane bami baqale ukubuza ngaye..



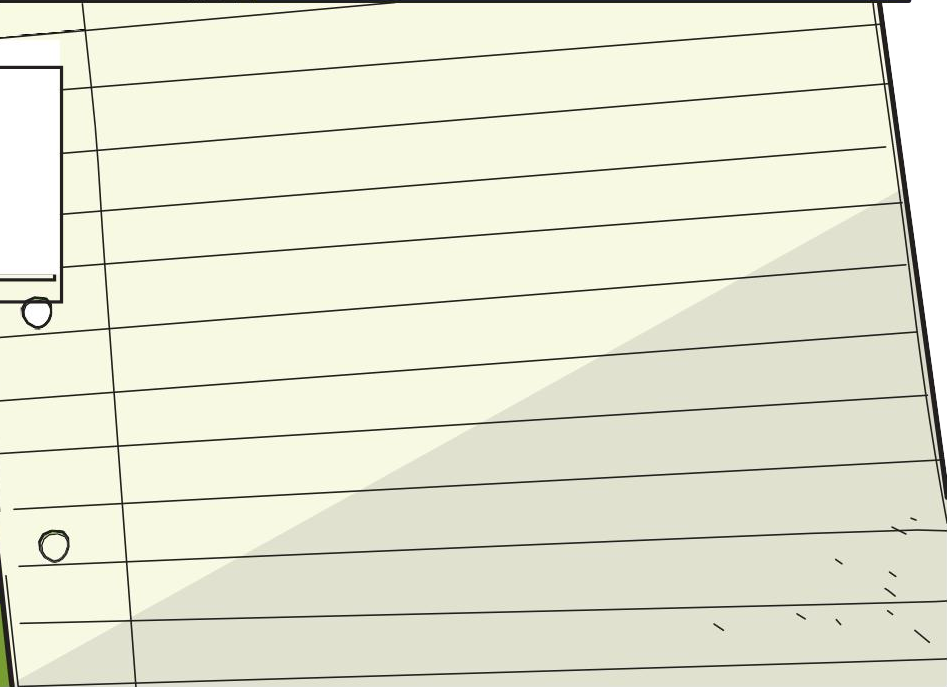
Okumnandi kakhulu ngendaba kaTristan ukuthi uthole ithuba lokutshela afunda nabo nge-ALS nangomkhulu wakhe. Akusiwo wonke umuntu ongenza njengoTristan. Ngakho-ke, uma uzizwa ungakathandi ukukwenza lokhu, kulungile nakho.


Yebo, Alison?

Esikoleni engangifunda kuso, babehlezi bengibuza ukuthi ubaba wami unjani. Eh futhi nothisha basabuza ukuthi ubaba wami uzizwa enjani. Eh futhi uthishanhloko naye uyabuza futhi.

Kuhle kakhulu lokho Alison. Ukukhuluma nesikole sakho kubalulekile. Nazi ezinye izindlela wena nabazali eningazicabanga nizisebenzise ukukhuluma nesikole.

Awunankinga nokukhuluma nothisha? Ungancamela ukuhlangana nabo bonke abantu noma ungancamela ukukhuluma nothisha/nomeluleki yedwa?



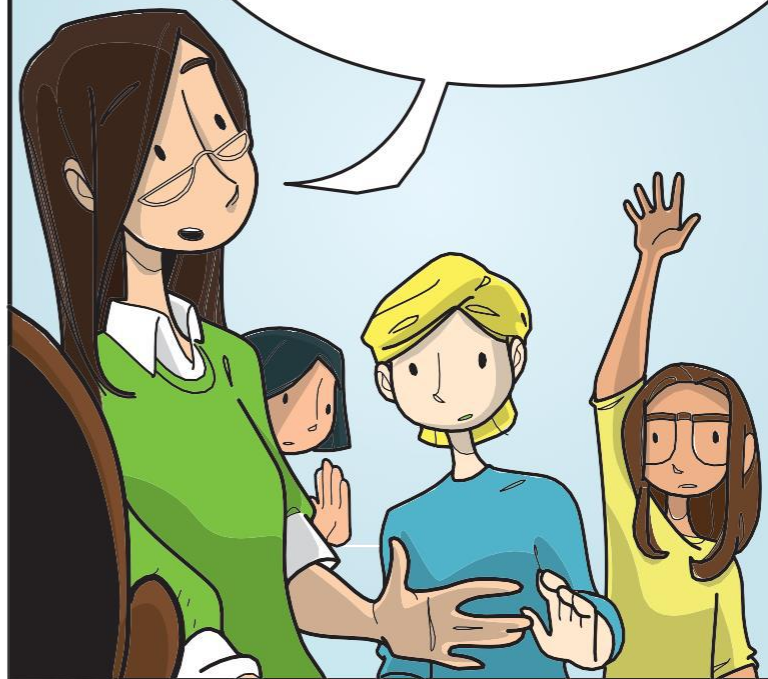


Yimina ngedwa eklasini lami onobaba ogulayo,
ngeke ngempela ngiye ndawo futhi.
Kodwa abangane bami bebe nomusa futhi bangisiza.

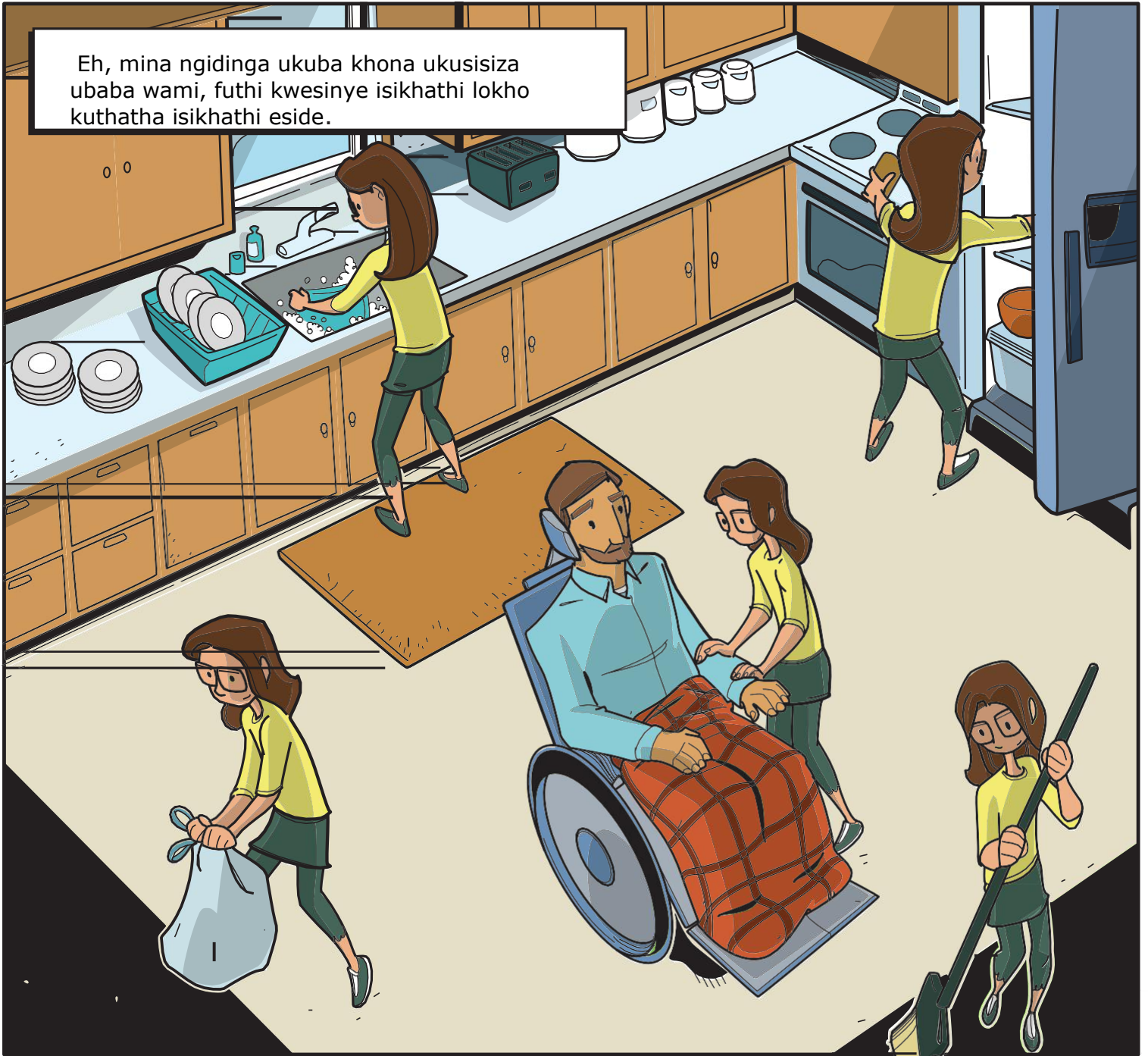


Siyabonga Yasmine. Ukukhuluma
nezinye izingane nge-ALS
kunzima, ikakhulukazi uma
kungekho Ilunga lomndeni wabo
eline-ALS, ngakho-ke uma ithuba
livuma kuhle kakhulu ukukhuluma
ngayo..

Sisakhuluma ngesikole,
bangaki kinina abangakwazi
ukuqeda umsebenzi wesikole ekhaya
ngoba umatasa usiza ekhaya
noma
usiza Ilunga lomndeni eline-ALS?



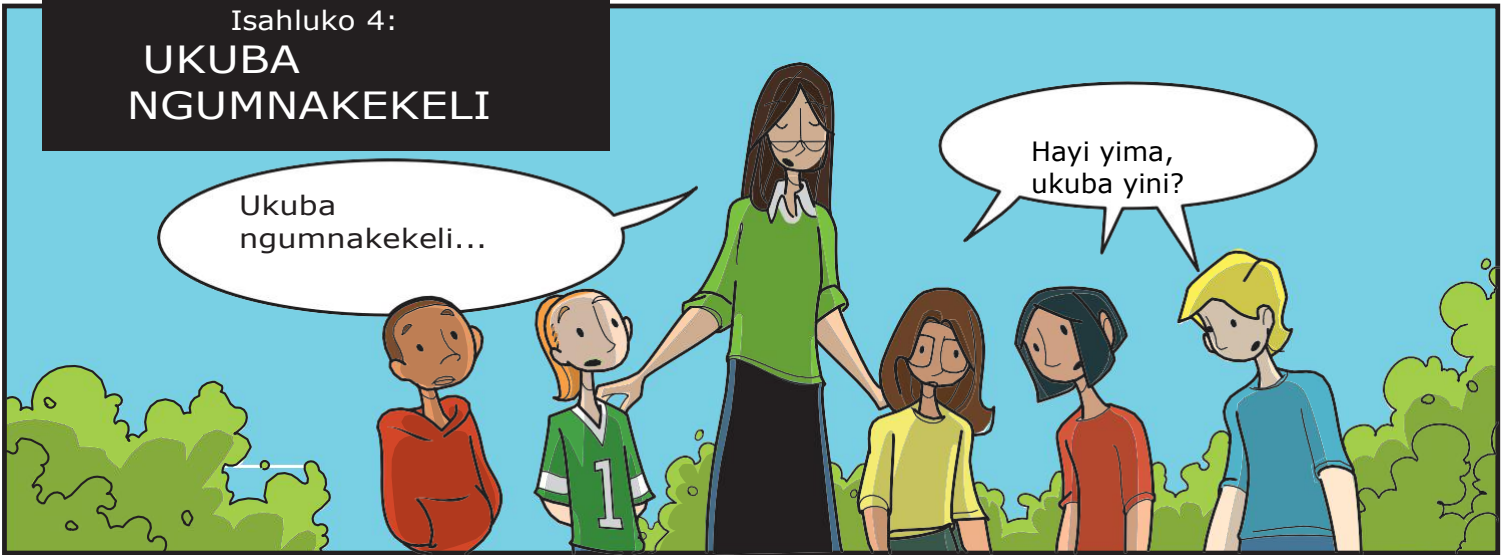
Eh, mina ngidinga ukuba khona ukusisiza ubaba wami, futhi kwesinye isikhathi lokho kuthatha isikhathi eside.



Eh washo khona Yasmine, yazi kahle kahle, iyo leyonto nqo, esizokhuluma ngayo manje-ukusiza umuntu one-ALS..



Isahluko 4:
**UKUBA
NGUMNAKEKELI**



Ukuba ngumnakekeli...

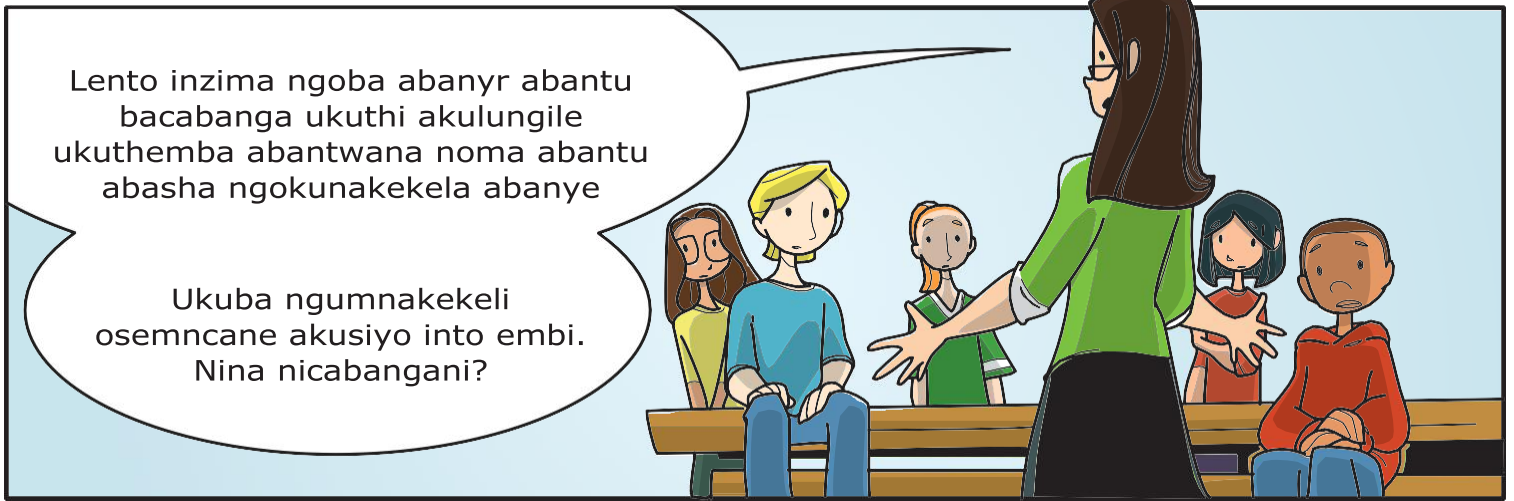
Hayi yima, ukuba yini?

Oh, awuthi ngibuyele emuva ngichaze... othisha nabacwaningi basebenzisa igama elithi "mnakekeli" ukuchaza umuntu owenza izinto ezizusiza noma abanakekela abanye abantu.

Lokhu kusho ukuthi abantwana abanjengani abasiza ukunakekela Ilunga lomndeni eline-ALS. Eqinisweni sike sabuza abantwana ukuthi bona bazibona njengabanakekeli na. Abaningi babi bathi yebo bazibona kanjalo, abanye bathi cha.

Hhayi ngoba benganakekeli kodwa ngoba bengathandi ukubizwa ngabanakekeli. Kulele kuwe!





Lento inzima ngoba abanyr abantu bacabanga ukuthi akulungile ukuthemba abantwana noma abantu abasha ngokunakekela abanye

Ukuba ngumnakekeli osemncane akusiyo into embi. Nina nicabangani?



Kunzima ukwenza ezinye ezinto ngoba umama udinga usizo oluningi. Njalo emva ngokugamanxa kwehora, ujwayele

Ungalucela kubani usizo?

Kwesinye isikhathi kunzima, kanti kwesinye isikhathi awubi



Ugogo uyasiza.

Usisi wami.

Umakhelwane wami.

Sinomnake keli.



Yiziphi izinto abantu abangazenza ukukusiza?

Ukungisiza ngimbeke kwi-wheelchai yakhe.

Ukungifundisa ukuthi ngenzeni nokuthi ngikwenze kanjani?

Kuhle kakhulu lokho!
Mihle yonke imibono
yenu! Yebo izingane
ezinjengani ziyadinga
ukusekwa nosizo
oluningi kakhulu.

?

Ngiwise umama wami. Eh!
Angimuwisanga kude kakhulu,
bengizama ukumyisa kwenye
indawo. Angicabangi ukuthi
ngenze into enhle, yena
akaninkinga kodwa mina
angizizwa kahle ngalokho.

Kufanele ukuthi
uphatheke kabi Brian!
Akusiwe wedwa oke
wenza into enjalo..

Ngubani ohlezi
azi ukuthi
wenzani?

Indaba kaBrian ikhombisa
ukubaluleka kokufundiswa
nokuthola ulwazi ngokuthi
umphakamisa kanjani
umuntu, nokwenza ezinye
izinto zokunakekela umuntu..

Singalucela
kubani usizo
lokuthi senze
kanjani?

Umama.

Usonhlala
kahle.

Udokotela.

Yebo! Mihle
imibono.
Ukunakekela
kunzima. Kufanele
uhlezi ucela usizo,
futhi ningakhohlwa
ngesosiyeshini ye-
ALS.



Nithini kodwa ngokuhle? Nicabanga ukuthi kukhona okuhle ngokuba umnakekeli?

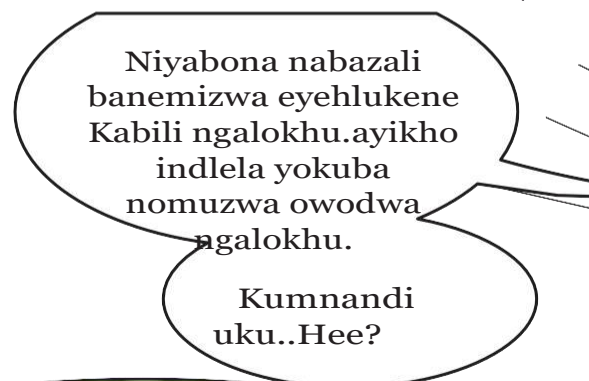
Esikhathini esiningi kumnandi ukuthi kukhona umuntu othembele kuwe ukuthi umsize, nokuthi uyakwazi ukumsiza esikhathini esiningi.



Ngiyabonga Yasmine. Kuyajabulisa ukwazi ukuthi usiza omunye umuntu. Uke izibuze ukuthi abazali bakho bacabangani? Sibuze abanye abantu abadala abane-ALS ukuthi kunjani ukusizwa izingane. Omunye uphendule wathi



“Kungiphatha kabi ukuthi bangibone nginje ebuncaneni babo, kodwa ngiyaziqhenya ngokuthi banozwelo. Abantwana bami basiza ngoba bethanda, hhayi ngoba bephoqiwe.”



Niyabona nabazali banemizwa eyehlukene Kabili ngalokhu. ayikho indlela yokuba nomuzwa owodwa ngalokhu.

Kumnandi uku..Hee?



Khuluma ngayo!

Lesi sihloko esilandelayo sifuna nikhulume....

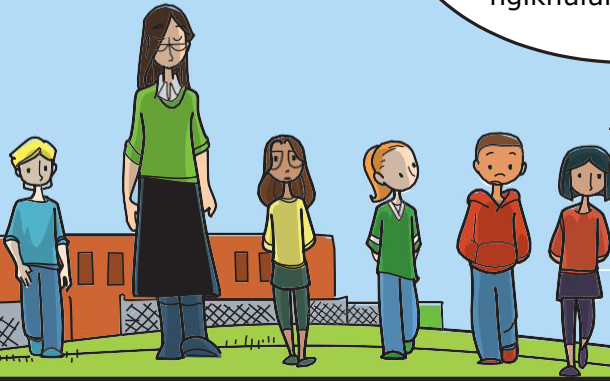
ISAHLUKO 5:
Ukufa, ukuzila
nokulahlekelwa,

Kungaba yingxoxo enzima lena.
Ukhona Phakathi kwenu
okewakhuluma ngokufa
nomama, nobaba wakhe noma
nomndeni wakhe?



Ngaphandle kokuthi
kube wuyena
okhuluma ngakho,
mina angeke
ngikhulume ngakho....

Ngoba ngingafuni ukumenza
ahlukumezeke emoyeni
ngaphezu ayikona manje.

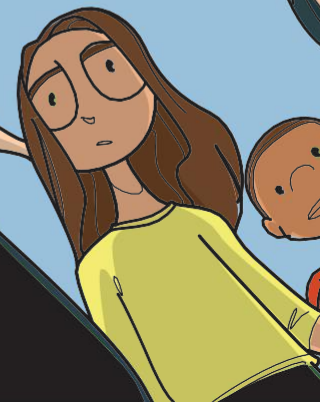


Ngiybonga Carrie. Yebo, kungasenza
sihlukumezeke emoyeni ukukhuluma
ngokufa noma ukucabanga
ngokulahlekelwa Ilunga lomndeni
wakho.

Kunzima ngempela. Uma
nifuna ukuthula isikhashana,
kulungile

Singaqhubeka?

Yebo.

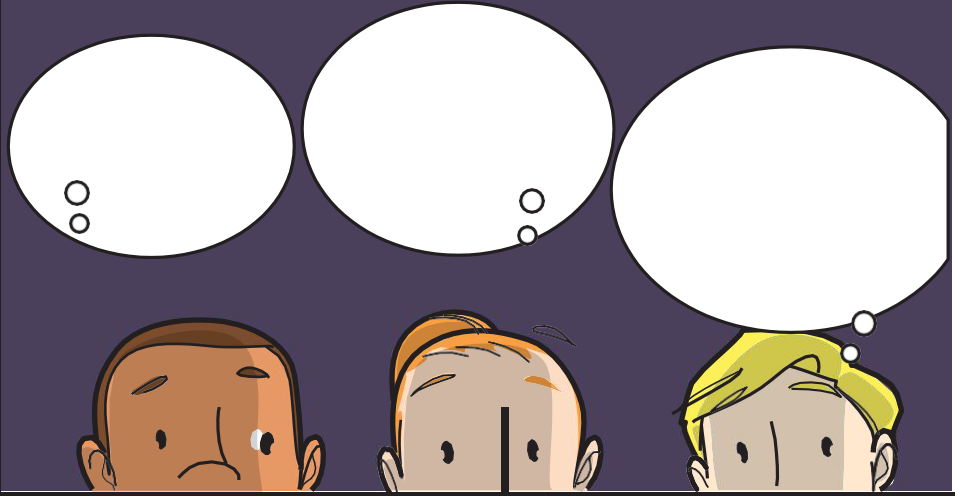


Kulungile, nanoma kunobunzima, ngelinye ilanga, sonke sizofa. Kodwa abanye abantu bafa phambi kokuba abanye bafe, nabantu abaphila ne-ALS. Kuyathusa ukucabanga ngokufa.

(Lelo gama...futhi!)



Ukufa kubonakala kunjani kuwena?



Kulungile ukungazi noma ukwesaba. Ngisho ukuthi, sisaphila futhi asazi ukuthi kuzoba njani. Ungaphinde uhlukumezeke emoyeni ngoba ulahlekelwa umuntu omaziyo futhi omthandayo.

Ukhona onomibuzo?

Kuzobe kunjani uma eshona?

Sizohlalaphi umama wami eshona?

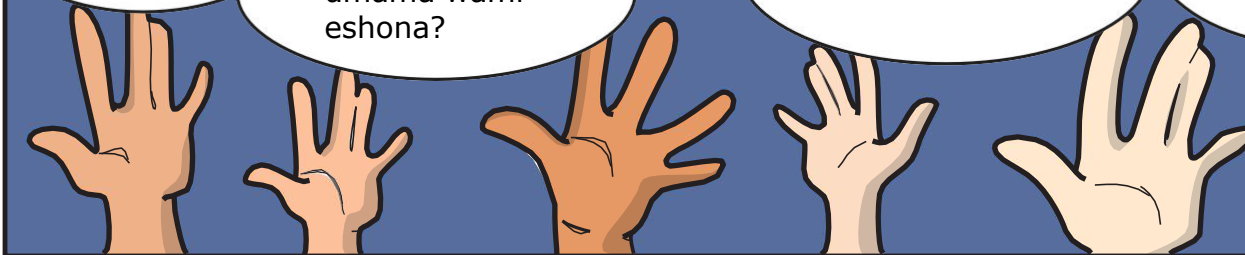
Kuzokwenzakalani ngami uma eshona?

Uzoba njani umgcwabo?

Sizohlala ekhaya na?

Ngizobe ngikhona uma eshona?

Ukhona ozoba nathi njengomndeni?



Yhoo! Yinhle Imibuzo yenu! Futhi inzima. Lezi yizinto ezibalulekile ukuthi nizibuze abazali benu. Kungaba nobunzima nakubona. Kodwa kuhle ukwazi ukuthi nifuna ukusizana.



Asihloleni uBella sibone ukuthi wazizwa kanjani ngenkathi ubaba wakhe eshona.

Uma ubaba eshona, ngangazi ukuthi kwenzakalani nokuthi kungani kwenzeka. Bekuyinto, engicabanga ukuthi, bengiyilindele, bekungcono kumina.

Bengazi emalangeneni ambalwa andlule ukuthi kukhona okuzoyenzeka. Ubebukeka njengomuntu oyedwa ukundlula amanye amalanga, bekangakhulumi kakhulu, nanekhompuyutha yakhe. Futhi ubaba ube thanda ukuhlala kuze kube sebusuku kakhulu. Kodwa manje, ubekhathala ngokukhulu ukushesha. Bekumangaza. Waseyashona, bengingazi ukuthi ushonile. Ngivuke usisi ekhala, bengicasukile ngoba angithandi ukuvuswa. Kodwa ke, uma i-ambulansi ifika, besengazi. Ngavele ngazihlalela ekamelweni nenja yami nayo ibididekile kakhulu..

Bekudabukisa futhi kungajwayelekile ukungamuzwa ethi 'HI SOURPUSS' (igama lesidlaliso ubaba ubaba wami wayelisebenzisa ngisafunda ubanga 3) njalo uma ngingena ngomnyango, kodwa kwangikhulula emoyeni, ukungasenzi umshini wokudonsa (ebengiwuwisa ngephutha, ngiyaxolisa)

Bekungajabulisi kakhulu, kodwa uyicabanga ngendlela ungcono ngokushesha. Ngiyecabanga



Indaba kaBella yinto nani enindlula kuyo.
Ukuzizwa udabukile, wesaba, nokungazi ukuthi
kuzokwenzekani.
Uma silahlekelwa umuntu, sizizwa sinosizi lokulahlekelwa

Usizi?

Yini lokho?

Usizi ukuzizwa udabukile, ukwatile, wethukile, ukulahlekelwa - zonke lezinto Ngasikhathi esisodwa...

Ingabe ukhona omunye wenu okewalahlekelwa umuntu?

Ugogo wami ushonile, bengizizwa ngidabukile. Ngakhala kakhulu. Kodwa umama wathi kuzolunga.

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?

Kuthiwani ngokuzizwa "ulahlekelwe" umngani omkhulu noma umzali nanoma asaphila?

Lokho kulahlekelwa kuyinxenye yosizi-futhi kujwayelekile.

Khumbula mhla uYasmine ethi akasazizwa enomndeni "ojwayelekile" hhayi-ke, lokho ukulahlekelwa, futhi unosizi lokulahlekelwa umndeni anawo njengoba izinto zishintsha.

Ubaba wami akasakwazi ukugwinya.

Nomama wami akakwazi ukukhuluma futhi ngikhumbula iphimbo lakhe kakhulu.

Uzizwa kanjani uma lezizinto zishintsha?

Sithi sisa jwayele okuthize bese kube khona okunye okungahambi kahle futhi

Sididekile.

Sidabukile.

Nanoma sizizwa kanje uma izinto zishintsha, kuhlezi kunomuzwa wokulindela ukulahlekelwa nosisi. Ungakhuluma nobani?

INGiyazi kufanele sikhulume ngayo, kodwa mangingafuni??

Umama wami.

Uthisha wami.

Umngani wami

Umbuzo omuhlu.

Ngaphandle kokukhuluma, okunye esingakwenza?

Kunganjani senze i-Art-ukudweba, ukusebenzisa ubumba ukuze sibumbe.?

Kukonke, ukulahlekelwa umuntu kunzima nawe uzizwa udabukile emoyeni. Kujwayelekile lokho.

yikuphi

Kukonke,
ukulahlekelwa umuntu
kunzima nawe uzizwa
udabukile emoyeni.
Kujwayelekile lokho.

Ungenza okuningi
ukubhekana nemizwa
yakho. Unayivaleli
ngaphakathi..

Siyazi, siyazi....

Khuluma ngakho!

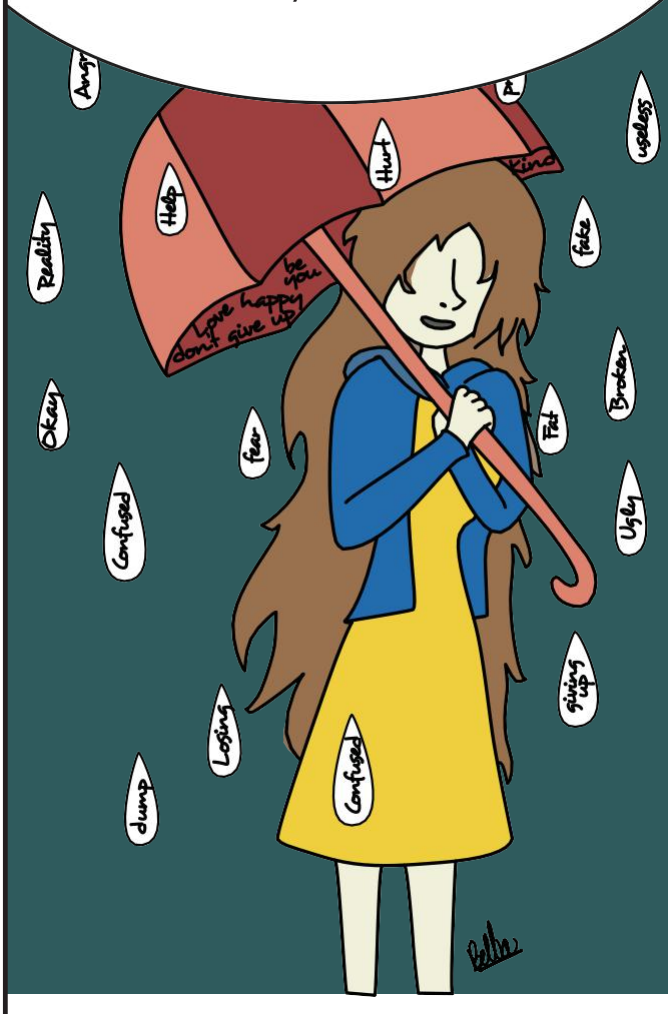
Niyamkhumbula uBella?
Nakhu akudwebile.

U

bedinga ukukhipha imizwa yakhe, futhi
kwezinye izinkathi kunzima ukukwenza
lokho. Manje, wazidweba ephansi
kwesambulela, wonke lamachaphaza
wemvula yimizwa yakhe. Ukukhuluma
nami lokho, mina ngikukhuluma nani.
Lena yindlela eyodwa yokuveza imizwa
yakho

Angifuni
ukukhohlwa ngobaba
wami uma eshona.

Kwezinye izinkathi ngizizwa
ndidabukile, futhi kulungile
nalokho. Bheka, ukulahlekelwa
umuntu akukalelelwe isikhathi.
Ungabakhumbula noma
usukhula futhi uhlangana
nabantu abasha, uya Esikoleni,
nanoma Uthola Umsebenzi.
Uyohlezi ubakhumbula..



Sesiyaqeda... kube wusizo yini lokhu?

Yebo!!

Ngijabule!
Bekumnandi
ukukhuluma nani
nonke – futhi manje
seniyazana

Singaqhubeka
kanjani sixhumane
ndawonye?

Ingabe uyaya
kumhlangano
we-ALS kwisonto
elizayo

Ithini inombolo
yakho
yocingo?

nginguBrian,
ngubani igama
lakho?

Izahluko zomhlangano weALS kuzindawo zenu zenza okukhulu ukuqiniseka ukuthi izingane izifana nani ziyaxhumana. Bathinteni, bazonasisa ngamahlelo noma inxaso abanayo yenu kanye nemindeni yenu.

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.



