

He Pukupuku Toto tō Joe



 leukaemia &
blood cancer
new zealand

our mission is to care, our vision is to cure



He mea hanga, whakaputa hoki
te putanga tuatahi nā:



Piritene Nui, 2003

me ngā mihi nui ki te Taiwhanga 27B
Starship Children's Hospital

he mea tautoko nā



He Pukupuku Toto tō Joe

nā

Victoria Barton

**Nā Tony Harris rāua ko Rebecca Jago
ngā Pikitia me te Hoahoa**



our mission is to care, our vision is to cure



Ko Joe tēnei. E noho ana ia ki tana Māmā, tana Pāpā, tana tuahine a Hayley, me tana pīpī teina a Alex.

He kurī tāna ko Scruffy te ingoa, he ngeru, a Harry, me te rua ika kōura a Bubbles me Beryl. He pai tonu ki a ia te purei poiwhana me tōna hoa, a Matt.

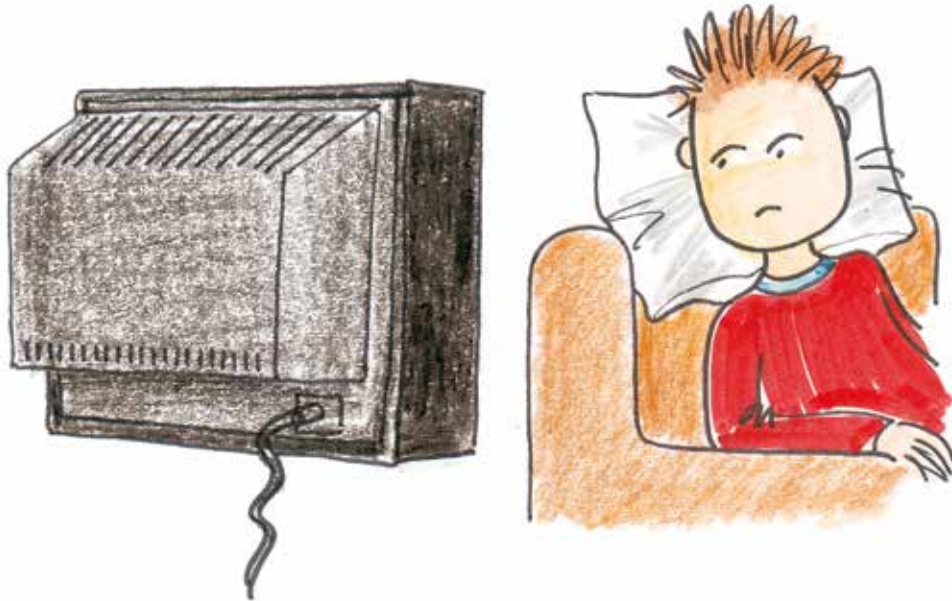


I tīmata te mate o Joe i tōna tau tuatahi i te kura, ā, tēnei te kōrero mō te aha i tūpono ki a ia.



Mō ētahi wiki i mate a Joe i te mare me te rewharewha.

Ka tino kōmā tōna āhua.



I ngenge rawa a Joe ki te tākaro, i pai noa iho ia ki te takoto me te mātakitaki i te Pouaka Whakaata. I tētahi rangi i kite tana māmā he marū katoa ōna waewae me tōna tinana, nā ka mauria ki te tākuta. Ka mea te tākuta me haere tika tonu a Joe ki te hōhipera.

Hei te taenga ki te hōhipera, ka mea te tākuta i reira me āta kimi e rātou te take i tino mate a Joe, ā, me noho ia mō ētahi rā.

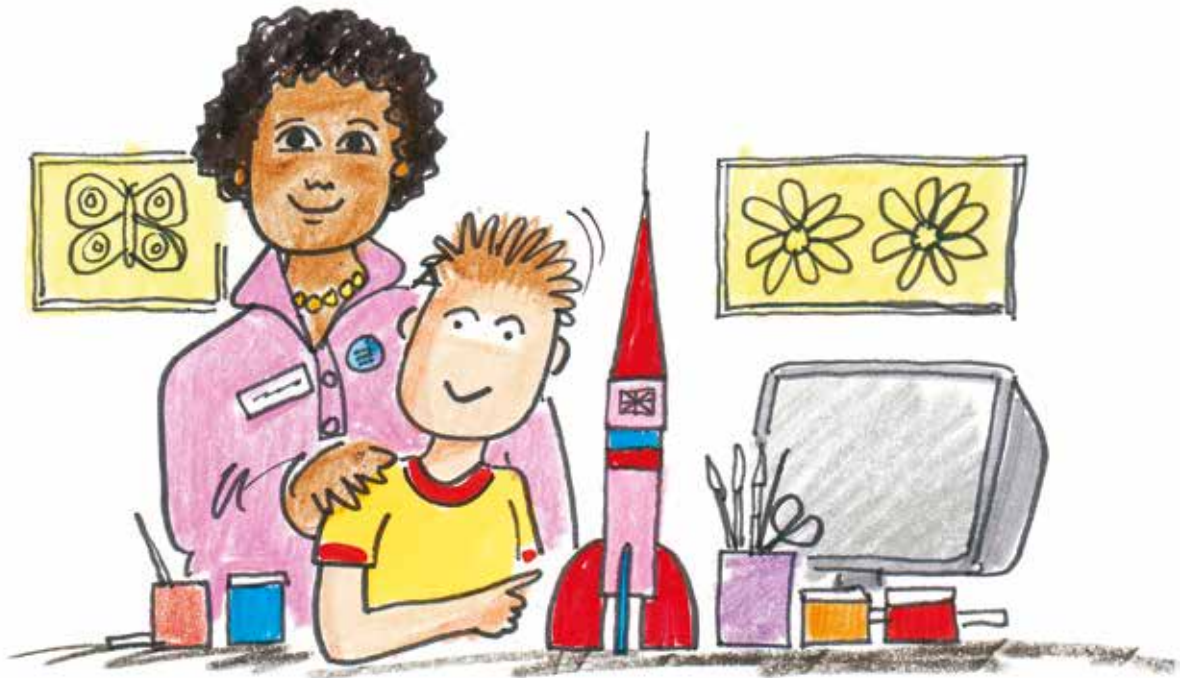


Ka tangi a Joe nā te mea e wehe ia i tōna tuahine me tōna teina, heoi i whakarite ōna mātua kia noho hoki a Māmā i te hōhipera, otiia kia toro atu a Pāpā, a tuahine, me te teina ia rā – ka hari anō te ngākau o Joe. He maha tonu ngā whakamātautau i mahia

ki a Joe, i mamae anō ētahi engari i reira a Māmā, a Pāpā rānei i ngā wā katoa hei awahi i a ia me te whakamihi i tōna māia.



I tino atawhai ngā tapuhi i a ia, ā, i hangā tahi e ia ētahi mea ātaahua me ngā mātanga tākaro, ngā kaiako hoki o te taiwhanga.

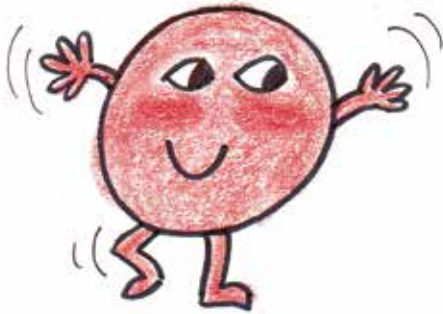


Me haere tonu a Pāpā ki te mahi, nā reira nā tana Kuia a Hayley rāua ko Alex i tiaki.

I tāwhai tonu ō rātou ngākau tētahi i tētahi, ka pīrangi noa a Joe kia hoki ki te kāinga.

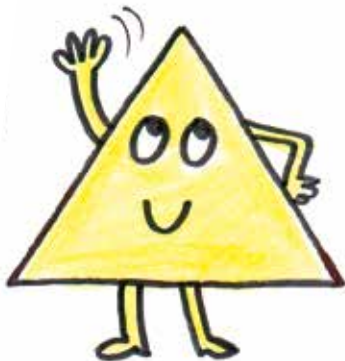
Ētahi rangi i muri mai ka kite te tākuta o te hōhipera i a Joe, a Māmā rāua ko Pāpā, ka whakamārama mai i tino mate a Joe nō te mea kua pāngia e te pukupuku toto.





Ngā Pūtau Whero

He maha tonu ngā rongoa ka whakamātauria e rātou kia pai ake anō ai ia. Ka ui atu a Joe ki te tākuta “He aha te pukupuku toto?” “Kāti”, ka whakamārama te tākuta, “Ko te pukupuku toto ko tētahi momo pukupuku, i tēnei wā ia, ina mate te wheketere i roto i tō tinana e hanga ana i ō toto. Arā anō ngā momo pukupuku toto rerekē. E huaina ana te wheketere i roto i



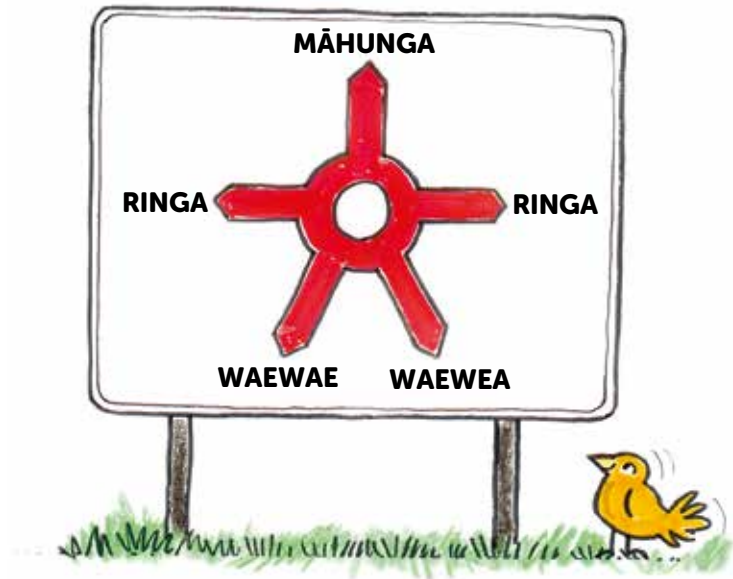
Plat Ngā Mōtepe

tō tinana ko te roro kōiwi, nā ko tēnei roro kōiwi kei roto rawa i ō kōiwi. E hanga ana te wheketere i ngā momo pūtau toto rerekē – ngā pūtau whero, pūtau mā me ngā mōtepe.”



Ngā Pūtau Mā

“Ina wehe atu te toto
i te wheketere ka rere
rā roto i ō ia-tuku me
ō ia-auraki. He rite ēnei
ki ngā ara e ahu ana
ki ngā wāhi katoa o tō
tinana.”



“E kawea ana ngā pūtau
whero i te hāora e ngā ai
koe ki ngā wāhi katoa o te
tinana; ka āwhina hoki kia
noho hauora koe, kī tonu
i te kaha”



“Ko ngā mōtepe,
ngā pūtau tuitui
rānei, kei te āwhina i
ngā ia-tuku me ngā
ia-auraki ki te tāmi i
te totototo ina motu
koe, ina marū rānei
i a koe anō, ā, hei
whawhai mate ngā
pūtau mā.”

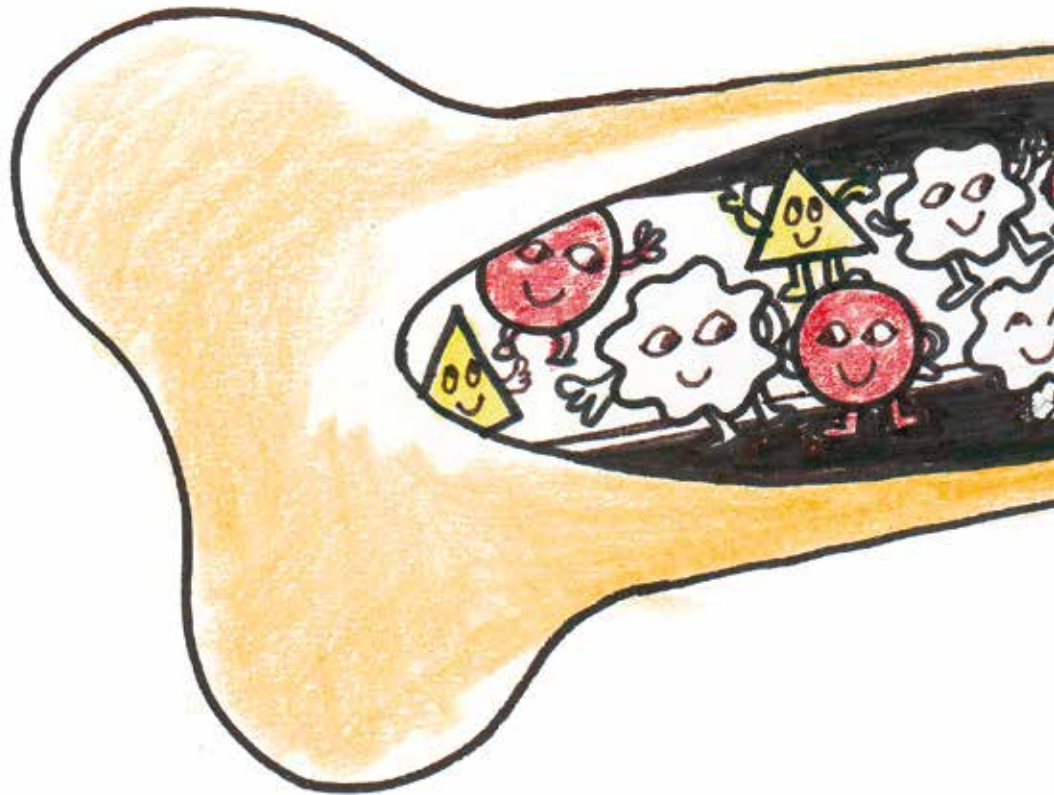
“Ina mate koe i te pukupuku toto, kei te hē te hanga pūtau
toto hauora i tō roro kōiwi. Kei te hanga kē ia i ngā pūtau pota
kāore e tika te mahi, kāore hoki e whawhai mate.

Nō konei i mate nui ai koe i te mare me te rewharewha.”

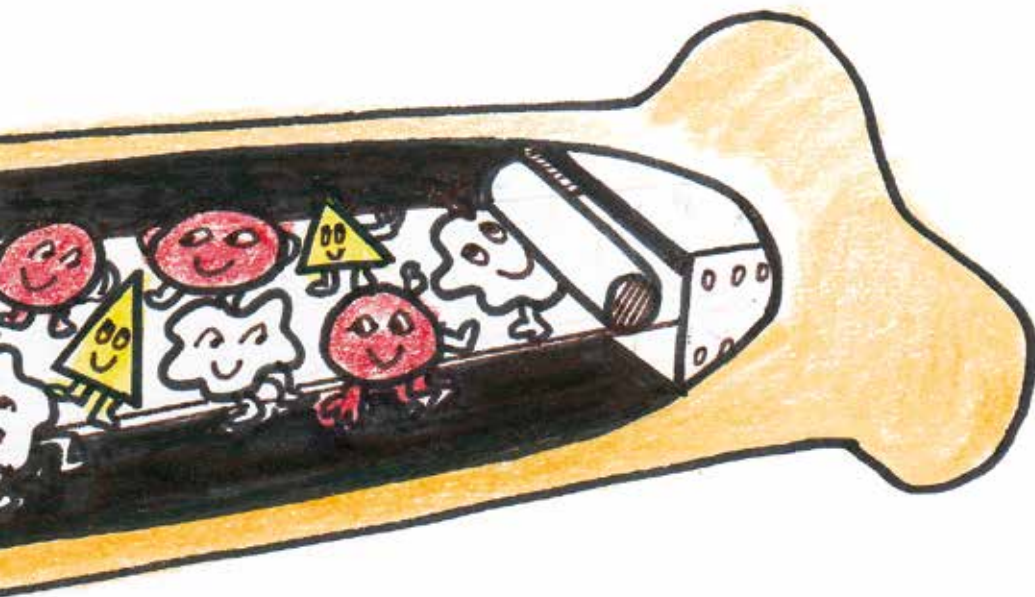
“Nā te tino nui o ēnei pūtau pota e hangā nei e tō roro kōiwi, kāore e rawaka te wāhi mō ngā pūtau hauora me ngā mōtepe hei tipu. Nā reira i tino ngenge ai koe, i kapi katoa ai i te marū ahakoa kāore koe i tutuki ki tētahi mea!”

“He māra rānei tō koutou? Ki te mea āe, ka mōhio koe i ētahi wā ka nui ngā tarutaru, otirā ki te kapi te māra i te tarutaru kāore he wāhi mō ngā putiputi me ngā huawhenua hei tipu. He pērā anō ngā pūtau pota i ō roro kōiwi; kei te kapi haere, ā, kāore e waiho he wāhi rawaka e tipu ai ngā pūtau hauora.”





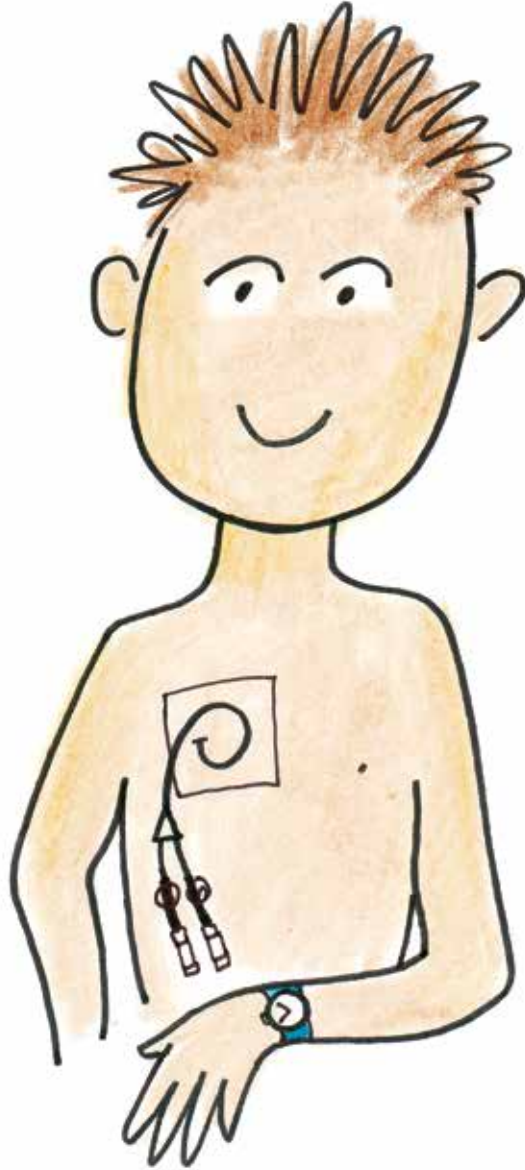
“Kāore tātou e mōhio he aha i pēnei ai, heoi e mōhio ana tātou kāhore rā tētahi mahi nāu, nā tētahi atu rānei i hua ai tēnei mate.” I ui atu a Joe hei āwhea ia ora ai, nā ka mea te tākuta, “E tūmanako ana mātou kāore e tino roa ka tika i a mātou te



mahi o tō roro kōiwi. Mā konei e whai rūma ai ō mōtepe, ngā pūtau whero me ngā pūtau mā kia tipu anō, ā, ka rongō anō koe i te pai.”

“Ka maha anō ō rongoā rerekē ka huaina nei he haumanu ā-matū mō tētahi wā roa, ahakoa e pai ana koe. Hei pire tonu ētahi o ēnei, ko ētahi atu he rongoā ka whāngaia mā te ngongo rongoā – he rerekē ngā momo, he Ngongokawe (Portacath), he ngongo PICC me te ngongo Hickman. Ka whakamahia te ngongo hei whāngai rongoā, hei tango whakamātautau toto, hei ārai hoki i te wero o te ngira.”

“Hei whakatūturu kei te whai hua ngā rongoā, kāore hoki ngā pūtau pota i te tipu ake anō, ka hiahia koe ki te whakamātautau toto, roro kōiwi, te wero tuarā rānei, rite tonu ki ērā kua oti nei i a koe.”





Nō muri mai ka
whiwhi haumanu
ā-matū a Joe rā te
turuturu i āpitihia ki
te ngongo.

Kāore tēnei i
mamae, engari i
rongo ia i te mate i
ētahi wā.

I te mutunga o te
haumanu ā-matū ka
kō te mīhini!

I hoatu hoki ki a Joe he huaranga toto kia nui ake tōna kaha,
kia pai ake anō.

I a Joe i te kāinga nā tana Pāpā
me tana Māmā i hoatu āna
rongoā, ā, ka haere atu te
Tapuhi ā-Rohe ki te
tango toto i a ia.





Rite tonu te haere a
Joe ki te hōhipera,
te tikanga me tōna
Māmā, engari ina
whiwhi wā tōna Pāpā i
te mahi, ka haere hoki
a ia, a Hayley, a pīpī
Alex anō hoki.
I kite a Joe i te tākuta
me ngā tapuhi, i
ētahi wā ka inea tōna

taumaha me ērā atu inenga. Rite tonu anō te tango toto i a ia
kia mōhio ai kei te pai te mahi a te haumanu ā-matū. I ētahi wā
me noho a Joe ki te hōhipera ina teitei tōna pāmahana. I haere a
Hayley ki tana Kuia noho ai.



Ka whakahoā a Joe ki ētahi atu i te hōhipera, ko Lucy te ingoa o tētahi; i pai hoki rāua ki te kōrero me te tākaro tahi, i mōhio hoki a Joe i mātau a Lucy ki ōna whakaaro mō te noho hōhipera.

I ngā wā kāore a Joe i te hōhipera, i tākaro tahi rāua ko tōna tino hoa a Matt. Ka tākaro kēmu rāua, pērā i mua rā o te matenga o Joe.



I tino takariri a Hayley i ētahi wā nā te nui o ngā perehana i whiwhi a Joe, ka mokemoke tōna ngākau. Kāore ia i pai ki te whakararu i a Māmā rāua ko Pāpā nā reira kāore i kōrero ki a rāua.



I tētahi rangi nā te tino hae o Hayley
ki tōna tungāne me āna perehana ka
peita ira ia ki tōna tinana katoa, kia
whakaaro ētahi atu kei te mate hoki
ia. "Auē e hine", ka kī a Māmā, "Kei
te mate hoki ko koe?" Nui tonu
tana awhi i a ia, ka peke a Scruffy
ka miti i te kanohi o Hayley ...
ka ngaro

atu ētahi o ngā ira! Ka mōhio a Māmā
rāua ko Pāpā kei te mokemoke pea
a Hayley. Nō muri ake i nui anō te
pārekareka tahi me Māmā rāua ko
Pāpā i ngā 'wā hari'.



I pātai a Joe ki ngā tākuta mehemea ka taea e ia te hoki ki te kura. Ka kī rātou ka taea mehemea i pai ōna tataunga toto. I tino rekareka a ia i te kura, i hari hoki te katoa ki te kite i a ia. I haere tahi a Joe me tōna tino hoa a Matt. I roto rāua i te karaehe kotahi, i āhei hoki rāua ki te noho tata. I ngā rā kāore i taea e Joe te haere ki te kura, ka hoatu he mahi kura hei mahi māna i te kāinga.





I tētahi rangi ka mate a Matt i te koroputa, nā reira me hoki a Joe ki te hōhipera mō ētahi rongoā kia kua ia e pāngia e te koroputa. Ka tino māuiui te tangata e mate ana i te pukupuku toto ki te pāngia e te koroputa, te karawaka rānei. Ka ora anō a Matt, ā, kāore i roa kei waho kē a ia e hākinakina ana.

Ka pēnei a Matt rāua ko Joe kātahi te mea rerekē ka hopukia te koroputa engari te pukupuku toto kāore i hopukia.

Mō tētahi wā kāore a
Joe i whai huruhuru.
Ka mea atu a Māmā nā
te haumanu ā-matū i
makere ai ōna makawe,
heoi ka tipu anō.
Mō konei ka pēnei ia
he rerekē ia i ētahi atu,
nā reira ia i whakamau
pōtae i ētahi wā, ina
koa i te takurua,
engari te nuinga o
te wā kāore ia i mau
pōtae.





I te taiwhanga hauora i kite a Joe i ngā tama me ngā kōtiro tokomaha, i ētahi kōtiro he wiki, i ētahi he pōtae, he kape, he kāmata, kua tipu anō ngā makawe o ētahi. Kōrero tahi ai rātou me te tākaro tahi.

I ētahi marama i muri mal, i te
taiwhanga hauora i te hōhipera,
ka mea a Joe ki te tākuta,
“Kei te rongō ahau he pai
tonu ahau ināianei, kei te mahi
hoki i ngā mea katoa e taea e
Matt, he aha te take me mau
tonu taku ngongo, me kai i
aku pire?”



Ka mea te tākuta, “Kei te tino koa ahau kei te pēnā tō pai. E hiahia ana tātou kia hari koe i ngā mea maha, engari me kai tonu koe i ō rongoā. Kāore tonu e mahi tika ai ō roro kōiwi kia kainga rā anō e koe ō rongoā katoa, nā reira me kai i aua rongoā mō tētahi wā roa tonu nei.”



“Hei tētahi rangi ka mutu ngā rongoā, ā, kāore e hiahiatia e koe te ngongo, te kai pire tonu rānei, heoi me haere tonu mai koe ki te kite i a mātou i te taiwhanga.”



I rongo tonu a Joe kei te tino pai ia. Ka haere ia ki te kura ka tākaro tahi me ōna hoa i reira, i te kāinga ka āwhina ia i tana māmā me tana pāpā, ka tākaro tahi me tana tuahine, me pīpī teina.



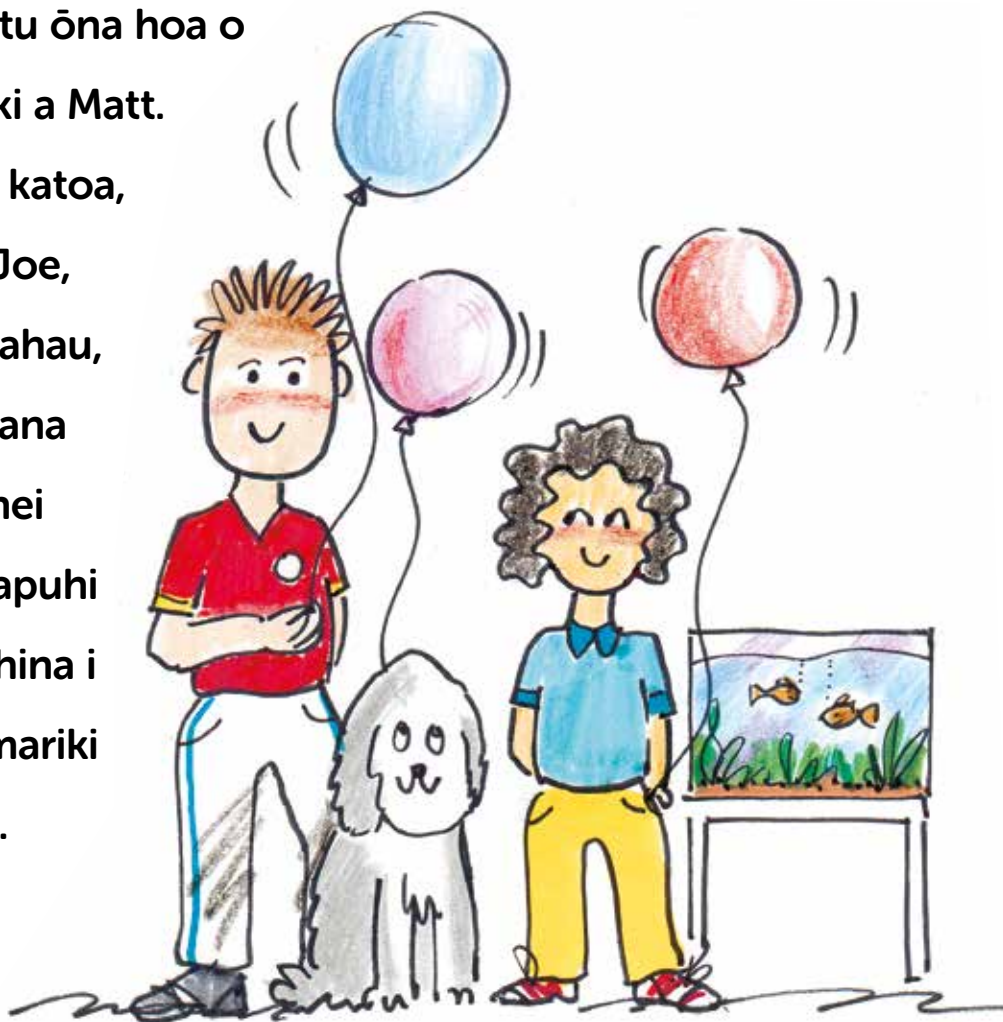
Kātahi ka tae ki te rā i
tāria roatia nei e Joe
rātou ko te whānau.
Ka haere ia ki te
hōhipera me Māmā
rāua ko Pāpā, ka mea
atu te tākuta, “Kātahi
te tamaiti māia ko
koe, kua tino pai rawa
tāu mahi!
Kua oti katoa tō
maimoatanga

ināianeī, ā, taro ake nei ka tangohia e mātou tō ngongo.
Me hoki tonu mai koe ki te kite i a mātou mō te tiroiro kia
tino mōhio tātou kāore i hoki mai te pukupuku toto”.

Ka tae anō a Joe ki te kāinga ka kite ia kua whakaritea e tana
Kuia me te whānau he hākari.

I tae katoa atu ōna hoa o
te kura, tae ki a Matt.

I tino hari te katoa,
ā, ka mea a Joe,
“Ina pakeke ahau,
e whakaaro ana
ahau kia tū hei
tākuta, hei tapuhi
rānei kia āwhina i
ētahi atu tamariki
pēnei i a au”.





Ka tū hoki koe hei aha ina pakeke koe?

Te tikanga o ēnei kupu

REHU ĀRAI MAMAE

Ina hoatu rongoā ngā tākuta ki a koe hei whakamoe i a koe i te pokanga,
kia kore ai koe e rongoi i te mamae.

WHAKAMĀTAUTAU TOTO

Ina tirohia he tauira iti o ōu toto kia kite e hia ngā pūtau whero,
ngā pūtau mā me ngā mōtepe.

HUARANGA TOTO

Ina pāpaku tō tataunga toto tērā pea ka hiahia toto tāpiri koe kia pai ake koe

WHAKAMĀTAUTAU RORO KŌIWI

I raro i te rehu ārai mamae ka tangohia he tauira o tō roro kōiwi i ngā kōiwi i tō
tuarā mā tētahi ngira motuhake

MATE PUKUPUKU

Ina kāore e tika te mahi a ngā pūtau i roto i tō tinana

HAUMANU Ā-MATŪ

He ranunga o ngā rongoā rerekē e maimoa ana i te mate pukupuku.

MĀTANGA TOTO

He tākuta ka tiaki i ngā tūroro me te tahumaero toto pēnei i te pukupuku toto

Te tikanga o ēnei kupu

NGONGO HICKMAN

Ka whakaurua i raro i te rehu ārai mamae he ngongo kotahi,
ngā ngongo e rua rānei, ka puta te pito i te poka iti i te kiri o tō poho.

PUKUPUKU TOTO

He momo pukupuku ina kāore i te tika te mahi a te wheketere
e hanga ana i tō toto

WERO TUARĀ

I raro i te rehu ārai mamae, ka werohia he ngira hei tango wē i tō tuahiwi,
i ētahi wā ka whakaurua he rongoā

KOREPŪTAUMĀ

Ina tata kore ō pūtau toto mā (ngā pūtau mā ka whawhai i te mate).
Ko te tikanga o te korepūtaumā ka nui ake tō mōrearea ka pāngia koe e te mate.

NGONGO PICC

He ngongo kotahi, e rua rānei ka whakaurua i a koe i raro i te rehu ārai mamae.
Ka puta te pito i tētahi poka iti i te kiri o tō ringa.

NGONGOKAWE

He ngongo ka whakaurua i raro i te kiri tata ki te kēkē i a koe i raro i te rehu
whakamoe, ka haere i raro i te kiri ki te uaua matua i te kakī.
Ka hoatu he rongoā, ka tangohia rānei he toto, ka pania he 'kirīmi wana' ki te
kiri e poki ana i te ngongokawe i te hāora kotahi i mua atu – kia kōpā taua wāhi
me te kore e mamae ina uru te ngira.



our mission is to care, our vision is to cure

**Ko Leukaemia & Blood Cancer New Zealand tētahi
whakahaere ā-motu i Aotearoa i whakaihia ki te tautoko i ngā
tūroro me ō rātou whānau e mate ana i te pukupuku toto,
te pukupuku taikiri, te pukupuku roro kōiwi, me ngā mate
toto pērā.**

**He rerekē te wheako o ngā whānau katoa; ehara i te mea
ngāwari te ora i te pukupuku toto, mate toto rānei, engari kei
a koe ētahi hoa tautoko.**

0800 15 10 15

www.leukaemia.org.nz





**Ki te mea he pātai āu, ki te ruarua rānei koe mō tētahi mea,
me pātai ki tētahi o tō kapa maimoa, whakapā rānei ki
Leukaemia & Blood Cancer New Zealand.**

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