THE 100 DAYS
AN ALLOGRAFT JOURNAL
TOKY THORNE
Dad, are you going to come to Pancake Day at school?

Sorry, Harvey, I'll be away in Melbourne.

Can we go out to the shed and make something?

I want Thunderbird Four.
DAY MINUS 8

MY DAD IS GOING TO MELBOURNE FOR 100 DAYS.
NO ONE BUMP THE TRIPOD OK?
JUST MOVE THEM A VERY SMALL AMOUNT.
AND DON'T MOVE MY GUY!
OK! OK!

NICE.

AND AGAIN.

DAD, THIS IS GETTING REALLY BORING!

...AND WHEN I GET BACK AT CHRISTMAS TIME, WE'LL GO TO THE SHACK FOR WEEKS AND WEEKS!

SEE... WE MADE A MOVIE.
DAY MINUS 6

I LOVE YOU SO MUCH

THE ROYAL MELBOURNE HOSPITAL

HICKMAN CATHETER
DAY MINUS 5  FIRST DAWN FROM ROOM 23  WARD 7B

CHEMO:
FLUDARABINE
CYCLOPHOSPHAMIDE
THOSE DRUGS PREP' ME FOR
KELLY'S STEM CELLS

DOCTOR JAMIE  1PM
OPHTHAMOLOGIST 2PM

COFFEE WITH
JENNY, PETER
MAC CAFE 330

RAMEN WITH
STUART 7PM
IN THE CITY

AS TIME GOES BY
MUSIC THERAPY
Day Minus 4  More Chemo

Tony, your electrolytes are low. We're going to top you up with some potassium.

And you had an issue with your eyes, you just had itchy eyes right?

No, according to the ophthalmologist I have pattern dystrophy. It's permanent, but I shouldn't go blind, I'll need checks annually. It's possible I've passed the gene to my boys.

7:30 PM Dr. David R. visits, head of the transplant centre.

There are just so many unknowns with an allograft.

True, but you are in the best possible position to get through this.

Stuart: Brother, carer, he visits every day.

There is nothing decent on at the Nova. Let's go eat.

We eat with Grace at Rice Cooker.
DAY MINUS 3

LAST DAY OF FLUDARABINE AND CYCLOPHOSPHAMIDE
PLUS POTASSIUM

OFF THE Drip Pole BY 2PM.

"THE POLE"
THE PUMP THROUGH WHICH ALL Drip INFUSIONS
PASS.

THIS WILL BECOME MY CONSTANT COMPANION
OVER THE COMING WEEKS.
DAY MINUS 2  REST DAY

NO DRIP, SO OUT
AND ABOUT.

NGV
BRAVE
NEW
WORLD

IS IT OK IF I JUST SIT HERE AND DRAW FOR A WHILE?
DAY MINUS 1

POTASSIUM DRIP FROM 6AM

A QUICK COFFEE
WITH JENNY BEFORE
20 HOUR CYCLOSPORIN DRIP,
(IMMUNOSUPPRESSANT)
BEGINNS AT NOON.

STUART VISITS AT 5

KELLY AND MARTIN
ARRIVE FROM HOBART 8PM.

BLOOD COUNTS 29/8, Hb 116, WCC 2.6, PLATELETS 104, NEUTROPHILS 2.4
DAY 0  TRANSPLANT

Cyclosporin finished 7am

My sister Kelly's stem cells being collected by 2pm at Peter Mac.

I wish I could draw, you can't really make a living from it though.

Stem cells delivered from the lab at 5pm. Transplant complete by 6pm.
7pm, start cyclosporin again, it will continue for two weeks.
DAY 1
Cyclosporin DAILY PLUS
Jen brings me a coffee
Slightly fatigued

7 PM DRESSING CHANGED METHATREXATE (A CHEMO DRUG USED TO STOP THE GROWTH OF KELLY'S T-CELLS WHICH CAN LEAD TO G.V.H.)
DAY 2

THE LAST DAY TO GET OUT BEFORE BLOOD COUNTS GO VERY LOW.

I MAKE IT TO THE PETER MAC ROOF GARDEN WITH THE POLE. AFTER TODAY I'LL BE CONFINED TO THE WARD.

Hb 114, WCC 12, PLATELETS 72, NEUTROPHILS 0.9
DAY 3

Hb 109, WCC 1.3, PLATELETS 67, NEUTROPHILS 1.0

LOOKING DOWN FROM 76
DAY 4

Hb 110, WCC 0.6, PLATELETS 55, NEUTROPHILS 0.3 (NEUTROPENIC)

The pump on "the pole" with cyclosporin the alarm goes off constantly, when I sneeze or when there is air in the line.
Sorry I didn't get these to you earlier.

We've got a few sickies on the ward but you seem to be doing so well I figured you wouldn't mind waiting.

And we can disconnect you for a while today.
DAY 7

Hb 105, WCC 0.4, PLATELETS 31, NEUTROPHILS 0.1
DIA 9

Hb 103, WCC 0.5, PLATELETS 19, NEUTROPHILS 0.2

THE VIEW FROM THE CORNER WINDOW AT 7B
BECAUSE YOU ARE DOING SO WELL AND YOUR BLOOD COUNTS ARE STARTING TO COME BACK UP, WE THINK WE CAN DISCHARGE YOU ON MONDAY.

A WEEK EARLY! WHERE WILL I STAY?
DAY 11

HB 106, WCC 0.7, PLATELETS 25, NEUTROPHILS 0.2

IT’S GOOD TO SEE YOU. IT’S BEEN ALMOST THREE WEEKS.

LUCY MAKES IT TO MELBOURNE FOR THE WEEKEND.

METHOTREXATE 11 AM
DAY 12

Hb 100, WCC 0.7, Platelets 19, Neutrophils 0.2

After the Methotrexate there will be nothing holding the new cells back.

Over the next fifty days, Cyclosporin will be your new best friend. It will allow the new cells to flourish.

The raised blood pressure is a common side effect. We will give you some pills for that.

Do not Google Cyclosporin or you will never take it.
DAY 13

46 103, WCC 9, PLATELETS 25, NEUTROPHILS .4

OK, SO DISCHARGE TOMORROW.

YOU HAVE BEEN THE EASIEST TRANSPLANT PATIENT WE'VE HAD ALL YEAR.
DAY 14

Hb 107, WCC 14, PLATELETS 39, NEUTROPHILS 0.7
(NOT NEUTROPenic)

THE NEW VIEW
CHETWYND ST.
NO DOCTORS
NO NURSES
NO HOSPITALS
FOR THE FIRST
TIME IN A
MONTH.
DAY 17

Trying to avoid the Hickman dressing in the new shower.
DAY 18

THE FIRST HAIRCUT SINCE MY HAIR FELL OUT SIX MONTHS AGO.
DAY 19

LUCY ARRIVES TO BE MY CARER FOR THE NEXT FOUR WEEKS.

JEEZ THIS KNIFE IS CRAP!
DAY 20

WAITING FOR BLOOD TESTS AND A DRESSING CHANGE 2B PETER MAC
DAY 22

THERE REALLY ISN'T A LOT TO TALK ABOUT TODAY.

YOUR BLOODS ARE LOOKING GREAT SO WE'LL SEE YOU NEXT WEEK.

EXCELLENT!

LET'S HOPE THIS DULL, UNEVENTFUL STORY CONTINUES.
Day 25

How did you sleep?

The steroids make it hard. Temazepam helps a bit.

Too many crazy dreams.

You seem to be doing well beyond the side effects of the drugs.

I guess, cyclosporin is a pain. It swells my feet and hands, raises my blood pressure and gives me the shakes.

It makes drawing hard.

It will all be worth it if I get a good outcome.

The doctors are optimistic.

Maybe, the next two months will tell.

That my blood counts have normalised means Kelly's cells have found a place in my bone marrow.

But how well that has worked is still unknown.

As they bring down my immune suppression, I'll either get rejection:

Graft versus host disease or success:

Graft versus myeloma
THE VIEW WESTWARD FROM CHETWYND ST.
DAY 27

SHORT WAIT FOR BLOODS AND DRESSING CHANGE
DAY 29

YEAH, IT'S GOING FINE BUT IT FEELS LIKE WE ARE GETTING TO THE POINTY END NOW.

THEY ARE GOING TO LOOK UNDER THE HOOD TOMORROW.
Day 31

Riding through Carson, wearing a mask.
I'm just worried about what can happen in my condition. It could all go pear shaped quickly.

Ok, hopefully I won't see you soon.

The nurse had a look at my blood results. She said the doc is happy not to see me about the sore throat.

Ok, good.

I just need to watch my temperature and let 'em know if anything changes for the worse.
THE VIEW TOWARDS NORTH MELBOURNE STATION FROM CHETWYND ST.
DAY 34

WAITING FOR BLOODS AND DRESSING CHANGE
Day 35

That carers session made me realise how easy we have had it.

At the session, they also explained that the duck bill masks were only good for half an hour.

Damn, I've been wearing this thing for weeks. Maybe I should not do this trip.

Cough

Crowded.

Could be a good idea.

Gotta try to remember to take it easy. Not out of the woods yet.
DAY 36

IT'S BEEN FIVE WEEKS SINCE I GOT THIS.

ROLAND WILL HAVE CHANGED SO MUCH IN THAT TIME.

Happy Father's Day!
DAY 37

STUART VISITS
CHEETHWYND ST.
DAY 38

LUCY ON HER BROTHER'S BORROWED ELECTRIC PIANO
CHETWYND ST.
DAY 39

A HAND OVER PERIOD!?  
MORNING MEDS

TWO MORE WEEKS IN MELBOURNE AFTER THE 100 DAYS.
TONE

WHY AM I ONLY HEARING ABOUT THIS NOW?  THEY DIDN'T MENTION IT WHEN I SIGNED THE CONTRACT.
TONE.

TWO MORE WEEKS AWAY FROM YOU, AWAY FROM THE BOYS...
TONE!

THEY ARE SAVING YOUR LIFE!  YOU JUST GOT THE BEST TEST RESULTS POSSIBLE -
TOTAL REMISSION.

YEAH, YOU'RE RIGHT, IT'S INCREDIBLE. BUT THOSE TWO EXTRA WEEKS IN MELBOURNE MIGHT JUST KILL ME.
DAY 40

GIVE ME A LOOK AT THOSE SPOTS ON YOUR BACK.

THEY AREN'T ITCHY. COULD BE THE FIRST SIGNS OF GRAFT VERSUS HOST DISEASE.

NAH, JUST DRY SKIN. YOU CAN HARDLY SEE IT.
VIEW TOWARDS THE CITY FROM CHETWYND ST.
DAY 42

That was another positive meeting with the doctor.

Oh come on, tone it's exciting!

Yeah, I know.

I want to get excited.

But there are still two whole months to go. That's two months of taking cyclosporin and waiting.

There is still plenty of time for things to go wrong.

Yeah, it's almost getting boring. Ha!
DAY 43

I just have to accept the way the drugs make me feel is the new normal...

...but it sure doesn't feel like it sometimes.

You mean the cyclosporin? You'll be on it until day 120. It's keeping yours and Kelly's cells in check and preventing GVHD.

One of the doctors described cyclosporin as my new best friend...
DO YOU THINK IT'S GRAFT VERSUS HOST?

IT'S A SYMPTOM THEY EXPECT.

THE DOCTOR I SPOKE TO ON THE PHONE SAID IT'S PROBABLY RELATED TO THE REDUCTION IN STEROIDS.

IT DOESN'T LOOK LIKE THERE ARE MORE SPOTS THAN LAST NIGHT.

THEY'VE JUST SPREAD A BIT.

THE SWOLLEN FEET ARE A PAIN TOO.
DAY 45

NOT RAISED, NO BROKEN SKIN...
AND IT SEEMS TO BE FADING.
DOES IT LOOK LIKE GRAFT VERSUS HOST?

G.V.H. CAN PRESENT IN A LOT OF DIFFERENT WAYS, AND THERE IS NO TEST FOR IT. WE WATCH FOR MULTIPLE SYMPTOMS AND TREAT THEM AS NEEDED, BUT I HAVE NO CONCERNS ABOUT THIS RASH, SO LET'S CONTINUE TO REDUCE THE STEROIDS.
DAY 48
CHIMERA
- Any mythical animal formed from parts of various animals.
- A thing which is hoped for but illusory or impossible to achieve.
- An organism containing a mixture of genetically different tissues formed by processes such as fusion of early embryos, grafting or mutation.

OXFORDDictionaries.com
DAY 50

So the drugs are driving me nuts, but the other thing is...

...What the hell is going on with my hair?

I kept it all through the chemo.

Most of it fell out with the melphalan during the autologous transplant.

Gradually hair returned. I was glad to have it back.

Now it's out of control. My beard is creeping up to my eyelids. My lashes have thickened. Brows are on the march. Hair is thick and curly and there is this dense fuzz on my ears, shoulders and front.
DAY 51

HAVING A GO AT MEDITATION
WELLBEING CENTRE
PETER MAC.
DAY 52

WELLBEING CENTRE GARDEN PETER MAC
DAY 53

Tony’s chimerism is 93% and aside from a slight renal impairment, all his markers are good.

And your wife has gone home?

Yes, she’s back with the boys now. It’s not ideal but it’s best for them. My brother is looking in on me most days now.

You know, it’s not unheard of for patients who have had to travel to go home before day 100. Let’s look at getting Tony home on day 75.

That would be soooo good!

But remember, all needs to go well for that to happen.
A NORTH MELBOURNE STREET FROM THE APARTMENT
THE SWELLING FROM THE BLOOD PRESSURE MEDICATION-AMLODOPINE IS GETTING TO BE A REAL DRAG.

IT'S VERY DIFFICULT TO STOP IT GETTING WORSE DURING THE DAY, EVEN IF I WALK OR SPEND A LOT OF TIME WITH MY LEGS RAISED.

...I HAD PRETTY TIGHT SOCKS ON SO FLUID BUILT UP ABOVE THEM AND ABOVE MY SHOES, AND THAT RASH- NOW MORE LIKE BRUISING-FORMED AT THE PRESSURE POINTS. THANKFULLY THE BRUISING DIDN'T LAST LONG, BUT I'LL STAY AWAY FROM THOSE SOCKS.

OK, LET'S DROP THE AMLODOPINE AND SEE HOW YOUR BLOOD PRESSURE IS ON THURSDAY.

AND THIS HAPPENED ON FRIDAY NIGHT...
DAY 56

Painting the roof next door to the apartment
STARTED DRAWING—IT STARTED RAINING
DAY 58

I'm concerned about your renal function. Can I put you on a drip now to give you some fluids?

NO.

My wife and kids have just arrived. They are waiting outside...

...and I haven't seen the boys for two months.

I'll drink more water.
DAY 59

REHYDRATION
DAY 60

I WENT TO CHAM AND I WENT IN D END RAND SCHOOL.

HARVEY'S DRAWING OF THE DAY:
I WENT TO A TRAM AND I WENT IN AN UNDERGROUND TUNNEL.
"TRAIN, ARE WE GOING ON THE (TRAIN)??"
DAY 61

ROLAND, HARVEY AND LUCY'S LAST DAY
The doctor, last week, was pretty concerned about my blood pressure, viral load, renal function, and my swollen ankles.

Oh?

Really? They are all what I'd expect.

What I mean is your test results are what I'd expect for someone on cyclosporin.

As the dose of cyclosporin is reduced over the next couple of months, we should see things returning to normal.

Phew!
VIEW TOWARDS THE ROYAL CHILDREN'S HOSPITAL FROM THE APARTMENT
DAY 64

I'M LUCKY. I GOT CANCER.

I GOT A RARE, BUT NOT TOTALLY OBSCURE CANCER: MULTIPLE MYELOMA.

I GOT IT WHEN I WAS "YOUNG AND HEALTHY" AND I GOT IT'S MOST AGGRESSIVE FORM.

THIS MEANT IT WOULD KILL ME WITHIN A YEAR WITHOUT A DONOR STEM CELL TRANSPLANT. THESE ARE RISKY. 1 IN 5 DIE DURING THE PROCEDURE AND IT HAS ONLY A 1 IN 3 SUCCESS RATE.

I'M LUCKY. I HAD A SISTER WHO WAS A GENETIC MATCH AND WAS WILLING TO DONATE STEM CELLS.

I'M LUCKY. IT'S 64 DAYS AFTER TRANSPLANT AND I'M STILL KICKING.

MOST OF ALL...

...I'M LUCKY TO LIVE IN A COUNTRY WITH SUCH AN AMAZING PUBLIC HEALTH SYSTEM.

YEP.
Day 66

Your renal impairment has spiked.

Oh, I'm surprised.

I've been drinking three litres at least a day.

Yeah, it's just the cyclosporin playing havoc.

Take a break from the cyclosporin tonight, resume as normal in the morning.

And I want to see you on Monday.

My poor kidneys.
DAY 6'7

POINT LONSDALE  MY FIRST TRIP OUT OF THE CITY IN TWO MONTHS.
THE TEST RESULTS WERE ALL GOOD TODAY, AND THE DOC EVEN MENTIONED GOING HOME NEXT WEEK AS LONG AS THE TESTS WERE GOOD ON FRIDAY.
DAY 70

NORTH MELBOURNE
With your renal function and viral load still a concern, you won't be able to go home at day 75.

OK

THANKS
Day 72

Five doctors have now looked at my renal function and viral load and said the same thing: this is being caused by the cyclosporin, we should look at reducing your dose.

Then, when it comes to it, they balk, leaving me on the same dose.

This is so frustrating and confusing.

I've had near perfect tests until now. For a day my cyclosporin was halved and nothing bad happened, so I can't see how a small reduction would hurt.

But hey, I'm just the patient, what do I know?

I know I don't want to wreck my kidneys, and I don't want these bad results to stop me coming home to you and the boys.

Yeah, but you don't want graft versus host disease either.
DAY 73

WAITING AT 3B PETER MAC
UNIVERSITY OF MELBOURNE
TRYING TO STAY IN THE SHADE
I've arranged for you to go home on Friday. Thursday will be your last appointment with us.
SO WHEN WILL I KNOW IF WE'VE ACHIEVED GRAFT VERSUS MYELOMA?

OH!

IT DEPENDS ON WHO YOU TALK TO.

WHAT, THIS IS CONTROVERSIAL?

YES, VERY WITH MYELOMA.

SAFER TO VIEW IT AS AN EXTENSION OF LIFE EXPECTANCY WITH AN IMPROVED QUALITY OF LIFE.

YOU MIGHT GET SIX YEARS.
Day 80

Going Home
DAY 81

HARVEY'S SWIMMING LESSON
DAY 82

MABEL
DAY 84

ROLAND
DAY 85
MR THORNE?

YES

YOU WERE SUPPOSED TO COME IN FOR A BLOOD TEST TODAY.

REALLY?

YES, YOU SHOULD HAVE BEEN GIVEN YOUR TWICE WEEKLY SCHEDULE ON MONDAY.

NO ONE GAVE ME A SCHEDULE. I THOUGHT I WAS ONLY COMING IN ONCE A WEEK.

OK, I'LL BE THERE IN TEN MINUTES.
Day 88

Story Time
DAY 90
Day 91
DAY 92

BACK TO MELBOURNE FOR THE ATOM AWARDS
DAY 93

HOME AGAIN
DAY 94

HARVEY, ROLAND & ANGUS, SCREEN TIME
DAY 95

LUCY, SCREEN TIME
DAY 96

HARVEY, PIANO LESSON
DAY 97

BATH TIME
Day 100

Canula inserted in preparation for Hickman's catheter removal.

Are we doing this straight or with drugs?
I want drugs.
...And right after that I went to Melbourne for an allogeneic transplant.

Jeez! Did it go OK?

I think so...

Dad!

You don't have to die yet Dad.

Roland - The day before he starts kinder.