

Aplastic Anaemia – My Story

Peter Wright

Symptoms and Reasonings

- New (additional) role a work - Tiredness
- Aching and swollen joints, wrists etc
- May 2021 – Pruning the bushes
- Time for a GP appointment – 3rd COVID lockdown
- GP App called LIVI – appt booked in on 28th May for 48 hours time
- Booked for GP bloods morning of Fri 11th June
- The answerphone message from hospital



First Presentation at Hospital

- Arriving at Bracken Ward
- Nurse check in
- Dr check in – consultant with reg
- Moved into a ward bed
- Pancytopenia – blood and platelet transfusions + B12 injections
- Stayed as an IP for 5-6 days
- Talked though neutropenic diet and went away with a whole load of drugs!

The Day Case Ward and Determining a Diagnosis

- Once discharged, attended Outpatients clinic on Birch Ward 3 times a week
- Within the first 2 weeks:
 - Continued with B12 injections
 - Hip bone marrow biopsy (mid June)
 - Conversations and thoughts (sick pay . . .)
- Narrowed down to differential diagnosis – Aplastic Anaemia or Myodysplastic Syndrome
 - (What felt like) a long wait for results from Bristol
 - Conversations of sibling bone marrow transplant

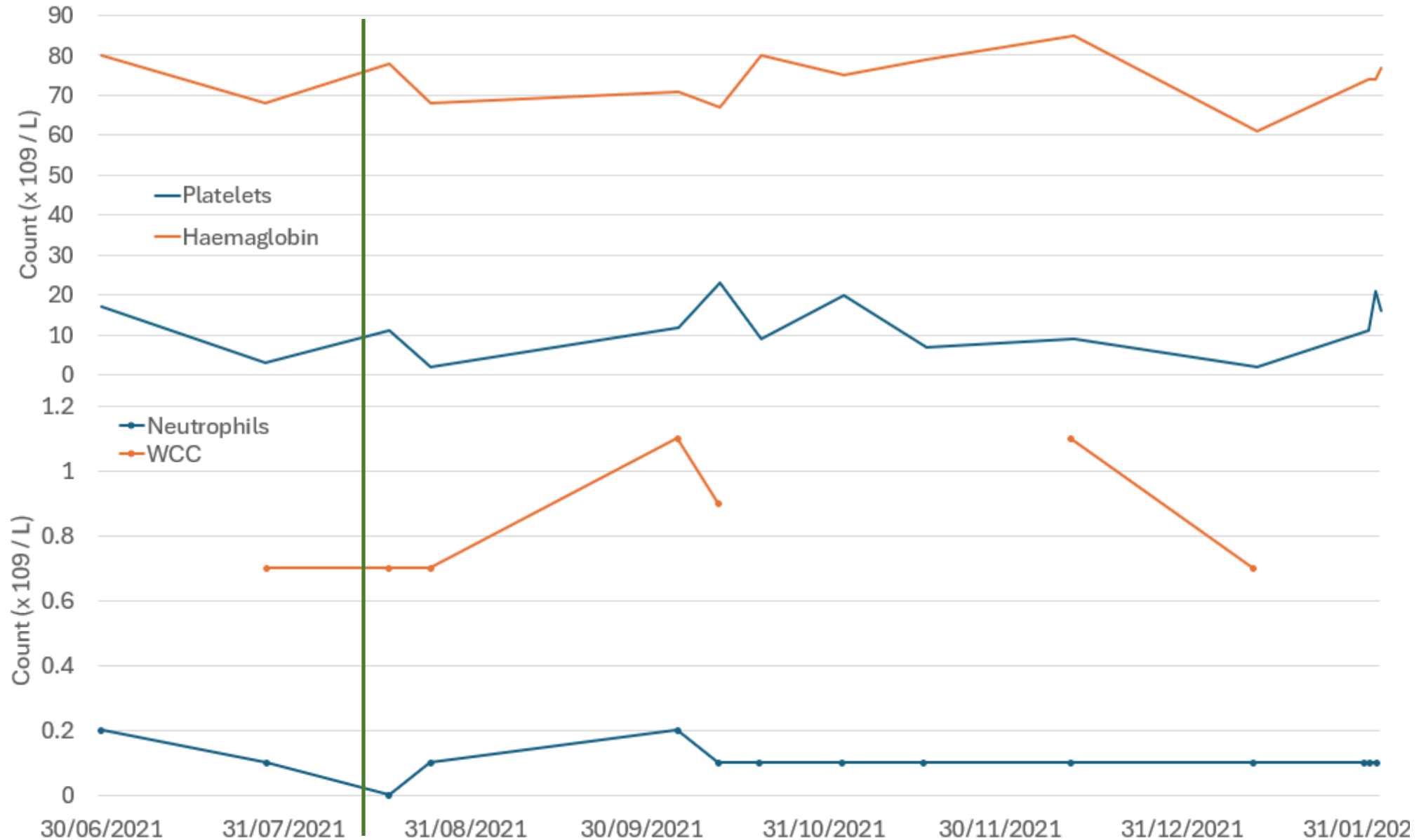
Determining a Diagnosis

- Unfortunately, my brother was not a match
- Diagnostics and genetic results were back

SEVERE APLASTIC ANAEMIA

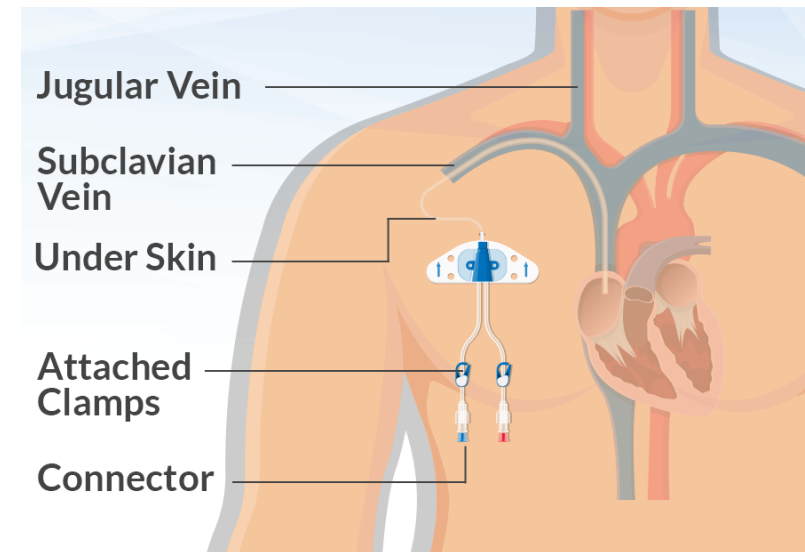
- What could have caused of my diagnosis?!?
- First line treatment pathway for horse anti-thymocyte globulin (ATG) at 39 years of age
- Time on the day case ward over the next few months
 - Where to sit
 - Fantastic staff and colleagues
 - Continued to work . . .

Timelines - Reaction



Plan A - ATG

- Consent – rigorous, an hour with the consultant going through everything and signing various documents
- 26th – Hickman line insertion – not a process I want repeating



- 29th August 2021 admitted to positive pressure IP room for ATG
- Continued to work, in my mind: keep to routine (keep distracted!)

Plan A - ATG

Summary	T	W	T	F	S	S	Day M	T	U	T	F	S
Drug	✓	2	3	4	5	6	7	8	9	10	11	12
IV Methylprednisolone <i>To reduce reaction to ATG</i>	*	*	*	*								
Platelets <i>To keep above 20 - 30</i>	*	*	*	*								
Chlorphenamine <i>To reduce reaction to ATG</i>	*	*	*	*								
Equine ATG <i>To treat AA</i>	*	*	*	*								
Ciclosporin <i>To treat AA</i>	*	*	*	*	*	*	*	*	*	*	*	*
Prednisolone <i>To prevent serum sickness</i>					*	*	*	*	*	<i>Aim to halve dose every 5 days</i>		
Ciprofloxacin <i>To prevent bacterial infection</i>	*	*	*	*	*	*	*	*	*	<i>Continue prophylaxis for at least 4 weeks</i>		
Voriconazole <i>To prevent fungal infection</i>	*	*	*	*	*	*	*	*	*			
Aciclovir <i>To prevent viral infection</i>	*	*	*	*	*	*	*	*	*			
Omeprazole <i>To counter steroid</i>	*	*	*	*	*	*	*	*	*	*	*	*
Norethisterone <i>For pre-menopausal women</i>	*	*	*	*	*	*	*	*	*	*	*	*

+ 40 °C

Steroids = WIRED!



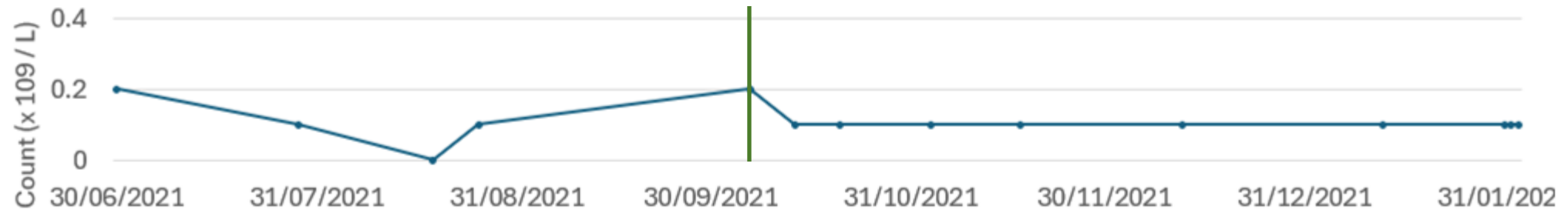
TICK TOCK !!!

Plan A - ATG

- Discharged on 16th September 2021
- Experience up to this point with sAA
 - Lithium man phenomenon
 - Bleeding, lots of bleeding
 - COVID in the house – confined to the Caravan for a few weeks
 - A (local) record with a platelet count of $1 \times 10^9 / L$
 - 2 or 3 in patient stays due to concern over infections (IV Tazocin, every 4 hours for 5 days)
- Returned to work pretty much straight away
- Did the ATG work . . .

Plan A - ATG

- 6th October 2021 (day 37) my neutrophils climbed to $0.2 \times 10^9 / L \dots !!$
- Alas, no – the next blood test a few days later had my neurophils at $0.1 \times 10^9 / L$ and that is where they stayed



- Conversations turned to Plan B – unrelated donor stem cell transplant
 - Heightened emotions – Christmas (Thank you Teddington Cheese Shop)
 - Would a donor be found – Ref patient waiting room conversation
 - If no donor, what other options: CAR-T?
 - Thoughts to life – should I write letters to wife and children, key milestones in their life
 - Lowest point – had to give myself a good talking to!

Plan B – Stem Cell Transplant

- Not 1, not 2, but 101 potential gene matched donors
- Recognition – Anthony Nolan Trust and British Bone Marrow Registry
- Had to undergo additional tests:
 - Cardiac US
 - Lung function tests
 - GFR – nuclear medicine
- Chosen donor – 36 yrs Polish man
- Date chosen for ward admission – 10th January 2022 . . .
- COVID on the ward delayed my admission to 26th Jan (thoughts to whether I would spend my 40th Birthday [March] in hospital)

Plan B – Stem Cell Transplant

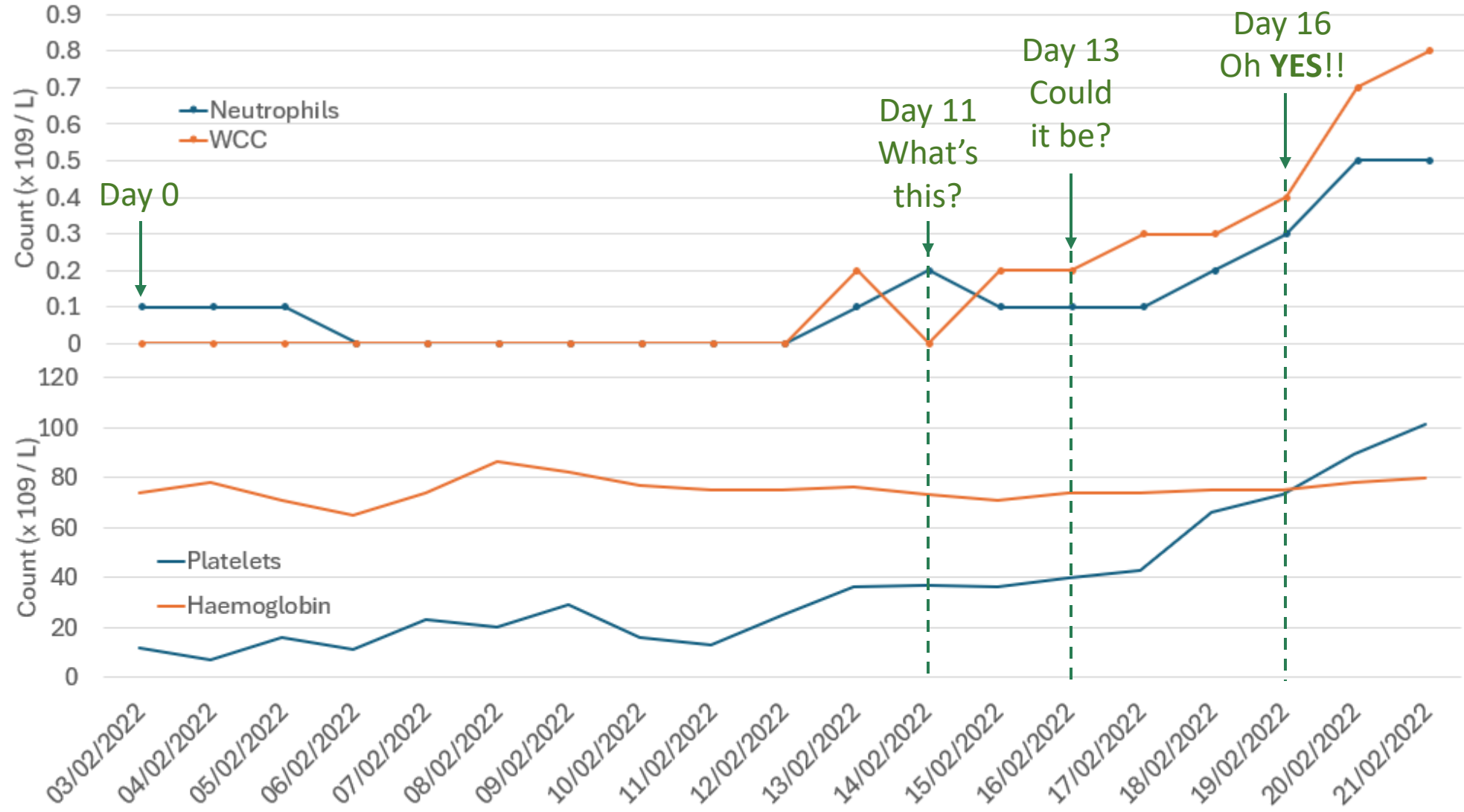
- Hickman line – not to be repeated . . . Unfortunately, not to be
 - Thank goodness for gas and air!
- After being admitted underwent chemotherapy to destroy what remained of my bone marrow:
 - Fluarabine;
 - cyclophosphamide;
 - alemtuzumab (Campath)
 - Was a Friday . . . Fish Friday
- Moved into positive pressure room and received 9 bags (with thanks to my fellow Clinical Scientist who arrived with the water bath and cryogenic tank) and my nurse that day



Plan B – Stem Cell Transplant

- Felt anticlimactic – stem cells went in over the course of a couple of hours
- Weeks went by with Winter Olympics, Netflix films, (beekeeping) books and the Sunday newspaper
- Day broken up by Dr ward rounds and mealtimes (thank you to hotel keeping staff!) with controlled caution of blood count numbers
- A week after Day 0, the lead transplant nurse came in and handed me a letter and being rather flustered that morning, left with no explanation
- It was from my (anonymous) donor
- Nurse returned to say I could reply (anonymously), but did I want to?

Plan B – Stem Cell Transplant



Post Plan B – Stem Cell Transplant

- Discharged on the 21st Feb 2022 craving a bowl full of salad and cheese on toast
- ~3 weeks before my 40th birthday
- Remained on therapeutic dose of oral cyclosporin for 12 months, tweaked depending on liver and kidney blood results
- A further 12 month tapering of cyclosporin

- Now, I'm off the drugs and had 6 months of 'baby vaccinations' with them all booked in, including my vaccination due it 14 years time!

And finally

- A huge thank you to all the staff on the inpatient (Bracken) and outpatient (Birch) wards
- Friends and colleagues who visited me in their lunch breaks and sat the other side of the glass door to keep me company
- To family, who visited and supported me during my time between treatments and beyond . . .
- 'Back room' colleagues – Biomedical scientists, Clinical Scientists, technical staff . . .
- And finally to my wife, Emma and children, Joseph, Anna and Hattie who supported me with their love and kindness throughout!
- Presenting to you now has helped me deal with what I went through – likely I will never fully comprehend my position

Questions and Suggestions

- Can I eat salad and cheese (neutropenic diet)?
 - Differing opinions amongst experts
- Once successful with BMT – continue with antibiotics or not?
 - sAA – minimal chemotherapy dose, affect to organs etc
 - 28 tablets = £1.62 (~£800 over 40 years)
- So . . . Is there research to explore who is more likely to respond to ATG (at a cost of (c. £180K)?
- Outstanding SAS Dr (Eva) on the day case unit – provided stability and consistency

ALWAYS have a good stock of Chicken and bacon mayo sandwiches



THANK YOU!