The Art of Oesophageal Cancer

A Visual Memoir Charting the Path Through Treatment, Recovery and Life Beyond Follow-up

The Artist and the Art in this Book

I was diagnosed with early oesophageal cancer in January 2018 and, with the exception of family history, none of the associated risk factors applied to me. About 75% of cases are largely preventable by eating a healthy diet, losing weight and by not smoking. However, for the remaining 25% of patients, the cause remains inconclusive. I also had no evidence of the pre-cancer warning stage, Barrett's oesophagus.

I've loved art since childhood but had only previously drawn diagrams to accompany notes at school or university. I'm not a trained artist and only started drawing creatively during my second cycle of chemotherapy. Drawing helped me tolerate side-effects and pass the time in the Chemotherapy Suite and during recovery.

I mainly use pencils and fine liner with lots greens, blues and natural tones. My style is figurative, using real objects; however these are often presented in fantasy/surrealist scenarios. Although not the most popular genre of art, it is incredibly versatile for illustrating thoughts and feelings.

As the weeks of recovery went by, my drawings grew in number and I decided to self-publish an art book. The first edition was very raw and the drawings were basic. However, a year after surgery and with an improved technique, I exhibited a few drawings in a small art exhibition in a local community centre. In February 2020, I posted a virtual exhibition on Twitter (#ocvirtualart), then on Instagram in February 2021, both for Oesophageal Cancer Awareness Month.

This latest edition contains a number of new drawings to mark living beyond follow-up at five years post surgery, with recovery from oesophagectomy forming the main theme of the book. The operation is also known as an "Ivor Lewis" and is named after the Welsh surgeon who pioneered the technique in the 1940s. It involves a two-stage process, where half of the oesophagus and a third of the stomach are removed and pulled out in one piece, through the back of the chest. A new oesophagus is then fashioned from pulling up the remaining stomach and joining it all up so the stomach forms a tube.

About this latest edition

A printed copy of this book will be sent free to upper gastrointestinal specialist nurses and dietitians in surgical centres, for their own reference and for sharing with patients and families in clinics or patient groups. This free e-book version is available to everyone to download at oesophagectomylife.co.uk.

Ann Wood, 2024

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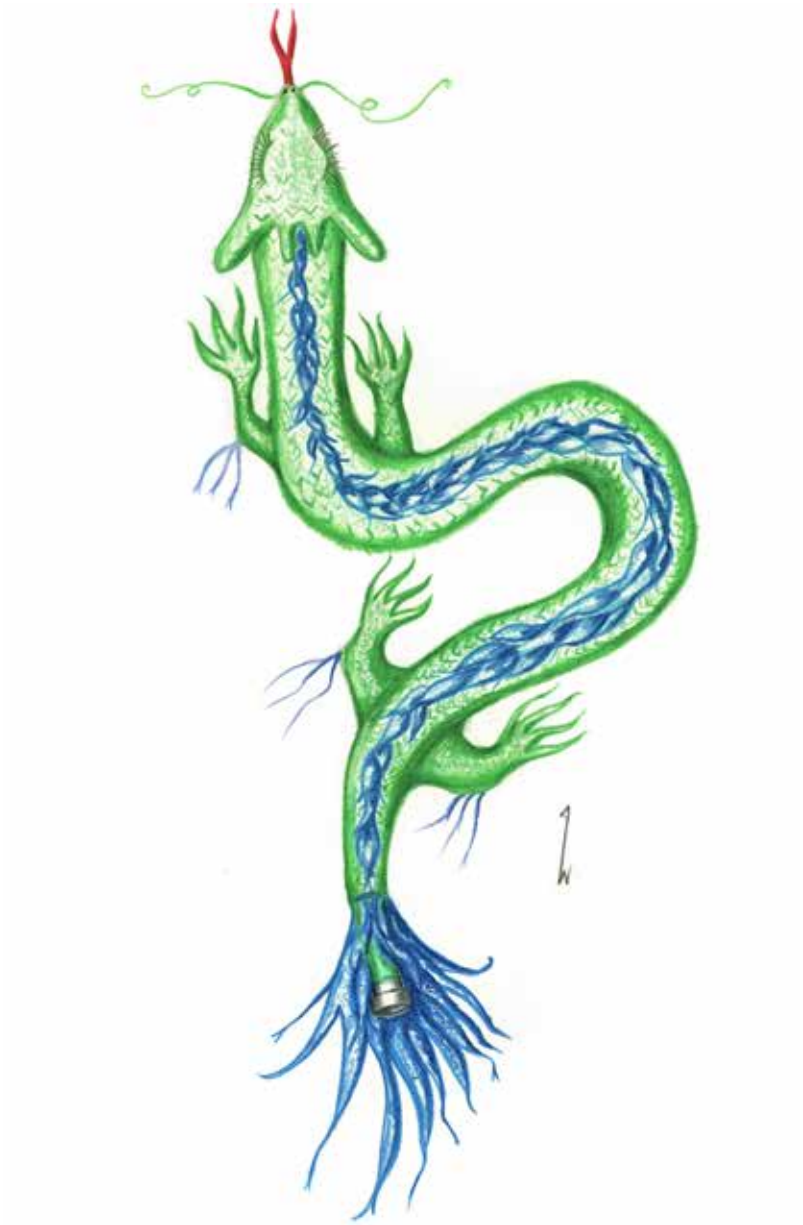
A Visual Memoir Charting the Path Through Treatment, Recovery and Life Beyond Follow-up

by

Ann Wood



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List of Illustrations

Introduction

In 2023, Noddy Holder from the 1970s glam rock band, Slade, announced he'd been treated for cancer of the oesophagus. He decided to go public to help raise awareness of the illness and support Christie Hospital in Manchester. The story ran for a while, but the media never sleeps and even the highest profile cancer campaigns are easily muted by national and global issues.

Oesophageal cancer gets neither the attention nor the funding of campaigns for more prevalent, easier-to-treat cancers, maybe due to its relatively low prevalence and difficulties around early detection. The sheer inaccessibility of the oesophagus means diagnosis is both invasive and expensive. So many people get heartburn, it is difficult to identify those at high risk as the majority of people referred on end up having a normal gastroscopy. For those with an abnormality, the best outcome is surgery but many tumours are found too late to make this a viable option. Finding an effective screening method remains a challenge.

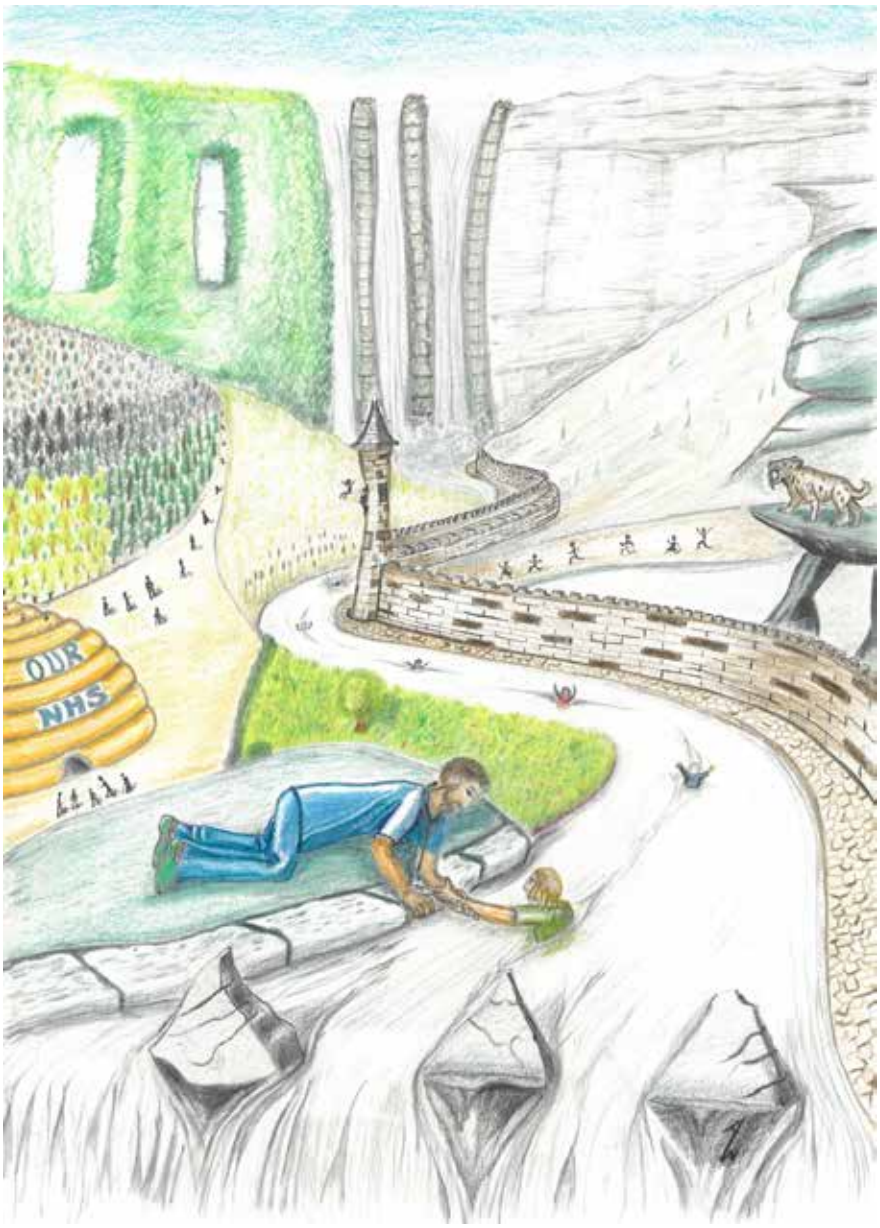
Noddy Holder is a rare celebrity survivor. *In Remembrance* below honours notable individuals who succumbed to the illness.

1. In Remembrance (January 2020)

Key left to right: Cars: John Thaw Brynmore Jones Library, Hull: Philip Larkin Motorbike: Barry Sheene
Hey 19: Walter Becker Stand Up Comedy: Jeremy Hardy Casablanca: Humphrey Bogart
No Man's Land: Harold Pinter Margate: Chas Hodge (Chas & Dave)

People rarely think about their oesophagus and why would they want to? It's out of sight and the word 'gullet' elicits a level of visceral revulsion not shared to the same extent by other body parts. The job of the oesophagus is to transport food and drink from mouth to stomach. Not much can go wrong with it, one would think. But it can! If it does, it's a major deal to fix.

I've tried to inject humour and lightness in the later pages but see no point in sugar-coating the treatment for oesophageal cancer. It is not for the faint-hearted. However, the process is doable and the right support is on hand to ensure as many people as possible are able to get through it.

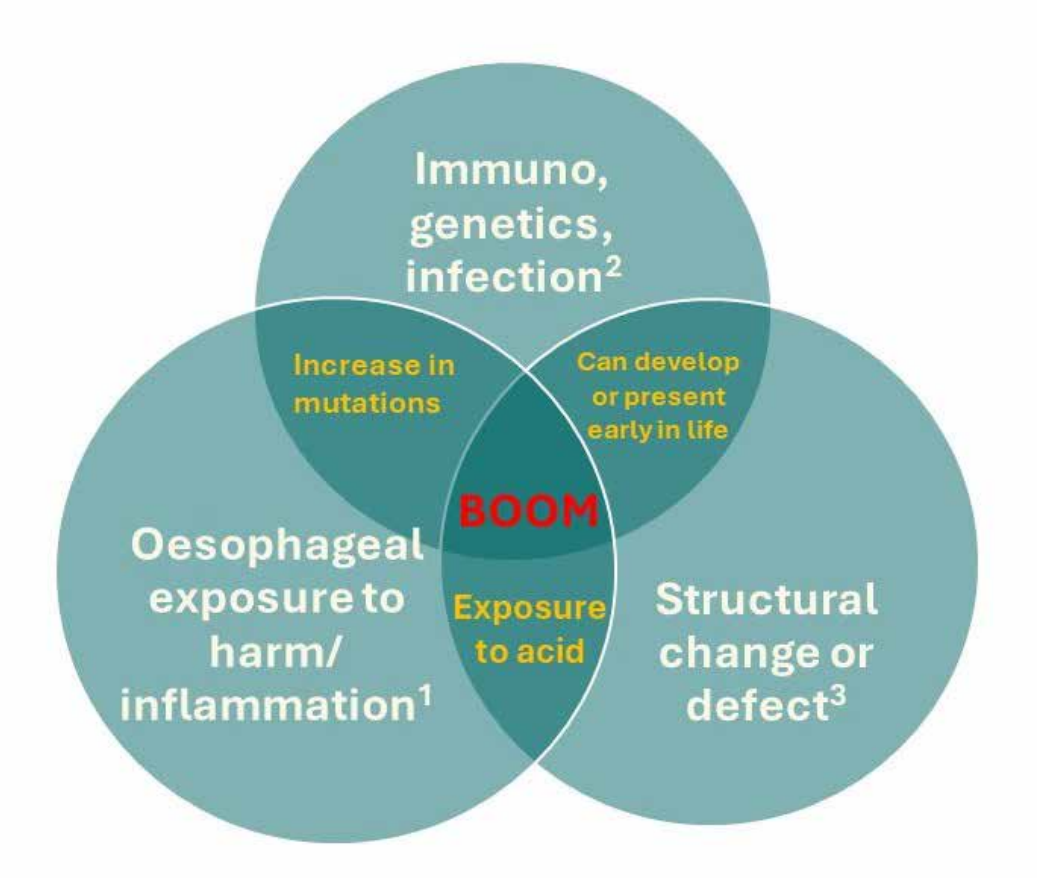


2. Upstream and Downstream Health Analogy (January 2020)
Irwin Kenneth Zola first used the 'upstream downstream' analogy to describe a sickness-based health system. He is essentially saying, instead of rescuing people from the river downstream, why not find and prevent who or whatever is pushing them in upstream.

Upstream, the people on the right are running from a sabre-toothed tiger towards the tower for shelter but ultimately, they have to jump or are pushed into the river to escape. Downstream is a front-line health professional fishing people out of the water, ahead of the rapids.

This drawing highlights the important work done upstream and out of sight, by researchers, epidemiologists and public health specialists, as they try to find causes and risks of disease. The 2020 corona virus pandemic brought these individuals into the limelight, with their data being used to advise governments, the media and the public. Similar groups of individuals work behind the scenes on oesophageal cancer, to identify ways to reduce the incidence of this less survivable disease.

I've used a sabre-toothed tiger to symbolise disease, as these carnivores used to be the main threat to early humans. In modern times, cancer, heart disease and infection are the modern-day predators. Illness is shown above on the more barren, right side. On the left, more lush side, health is restored or improved. Anyone can find themselves on the right side of this valley. As we age, our big cat's territory reduces in size and illness can occur more readily.



3. The Perfect Storm (January 2020)
The Perfect Storm is a Venn diagram created for my virtual exhibition on Twitter in February 2020. It shows the conditions required for the onset of oesophageal cancer. The exact mechanisms are not fully understood but it is likely to be a combination of genetic, immunological, physiological and environmental factors.

Below is an expanded list of risks taken from the medical literature, under three categories:

A Oesophageal exposure to harm/inflammation
Stomach acid, smoke, alcohol, very hot tea drinking and high consumption of salted food
(NB last two mainly in Japan, Korea, China)

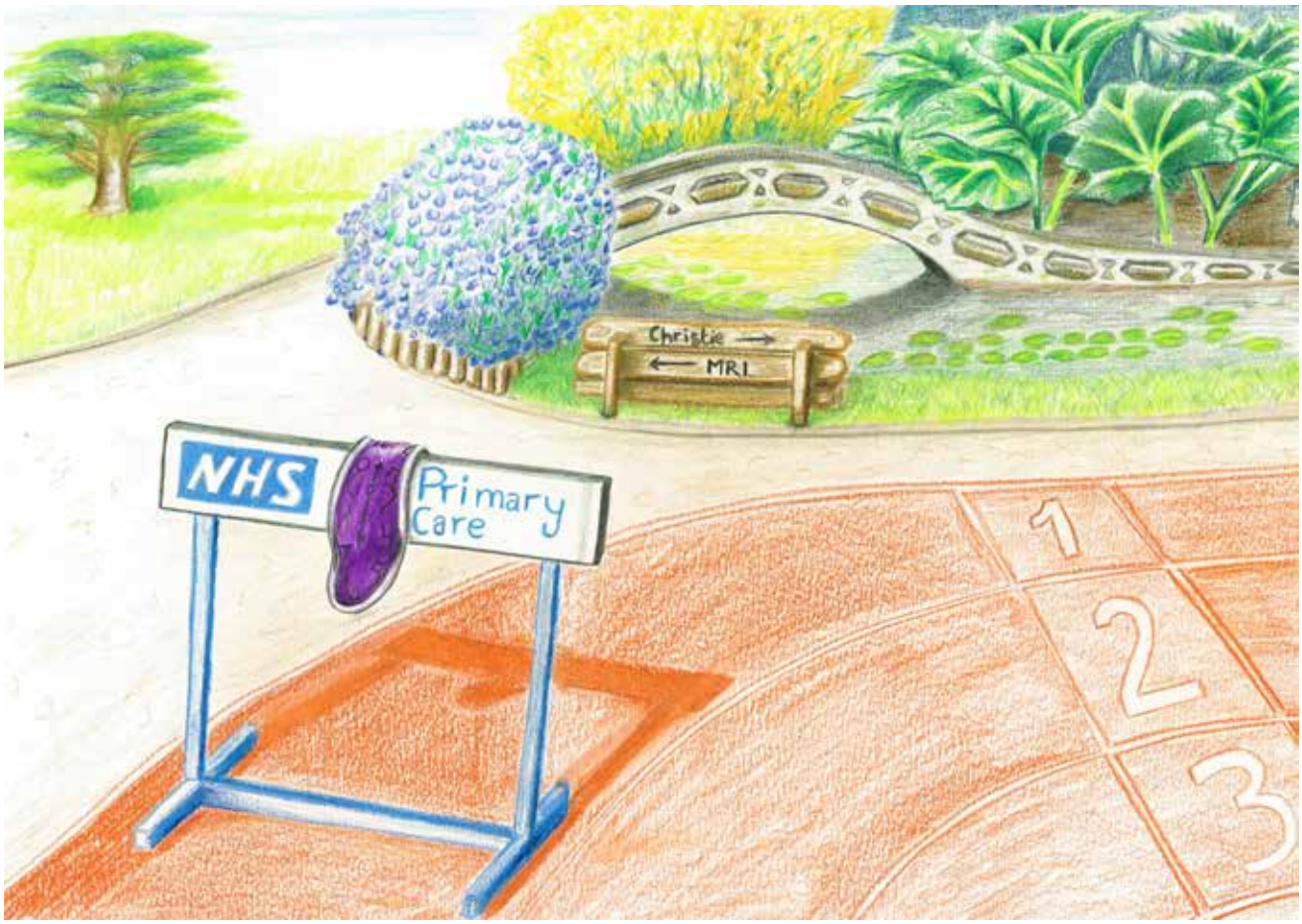
B Immuno-genetics or infection
Family history, blood group A (link to stomach cancer), Y chromosome, stress, bacterial/viral involvement, increasing age

C Structural change/defect/pressure/weakening of lower oesophageal sphincter (LOS) causing gastric leakage
a) hiatus hernia, achalasia, poor transit through gastrointestinal tract, obesity
b) food/drink that loosens the LOS and aggravates gastro-oesophageal reflux disease (GORD) and laryngopharyngeal reflux (LPR), notably alcohol, nicotine, caffeine, carbonated drinks, peppermint tea, chocolate, spicy foods and eating too much or too quickly
c) exercises/activity that could, over time, weaken the LOS and aggravate GORD/LPR or a hiatus hernia (e.g. heavy gardening, inverted yoga poses, abdominal crunches, waist restriction)
d) LOS relaxing drugs

4. Barrett's Pinball (May 2020)
This was drawn for World Barrett's Day on 16 May 2020. It shows development and treatment around Barrett's oesophagus as a game of pinball. Patients often experience going back and forth to their GP with their heartburn, so it can take a while for Barrett's to be identified (see also *The Race Against Time*).

Barrett's oesophagus occurs when the structure of cells on the surface of the oesophagus toughen up after long-term exposure to stomach acid. In a very small percentage of people, the toughened cells turn into cancer. It is not known why this occurs in some but not others, as many people can live for years with Barrett's and die of unrelated causes.

The various permutations, pathways and treatment options around Barrett's all get a mention in this game. Endoscopic surveillance is the best way to flag up early pre-cancer changes so patients can be treated and have a better chance of survival, while various flippers aim to propel people towards surveillance and away from premature death.



5. The Race Against Time (May 2018)
Like *Barrett's Pinball,* the above image refers to difficulties some patients have in convincing their GP their symptoms are serious enough to warrant further investigation. This is especially in the absence of red flags, such as weight loss and swallowing problems. Patients can often visit their GP several times before action is taken and this can be frustrating. It also leaves more time for tumours to become more established, ultimately reducing the range of treatment options open to the patient (see *State of Play*).

To secure more early diagnoses, patients need to present early and GPs need to be professionally curious over symptoms, especially common ones, like heartburn. Family history, lifestyle and anaemia could also be clues and investigation is better than masking issues with a prescription for omeprazole.

Once diagnosed, a patient with oesophageal cancer lands in secondary care on a well-established, multi-disciplinary pathway. The difference between negotiating primary and secondary care is portrayed above by a despondent Dali clock, drooping over a hurdle against the backdrop of a walk in the park. The garden scene is based on Tatton Park. This features a beautiful Lebanese cedar tree and an elegant bridge in the Japanese Garden. Also featured are enormous giant rhubarb *Gunnera manicata* and yellow azaleas and a blue ceanothus.

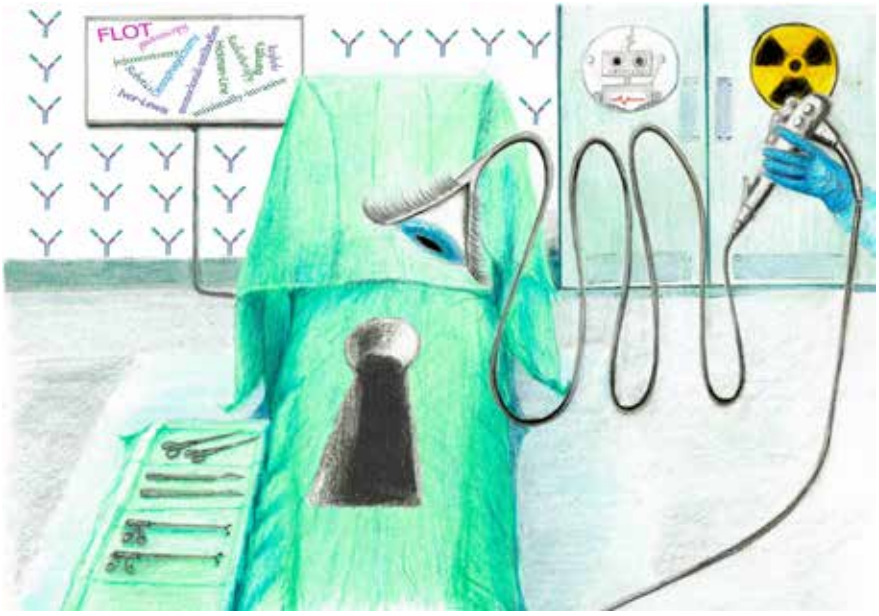
Diagnosis via gastroscopy is unpleasant for patients and resource-heavy for the NHS. However, there are a few less-invasive, patient-friendly diagnostic tools being developed for GPs. These include the Cytosponge™ and an AI-based algorithm using combined symptoms to assess overall risk. These are still being tested and are promising innovations but they'll only work if significant numbers of patients present with demographics and symptoms ticking the right boxes. If they don't, the hurdles will remain in the way.

6. The Uninvited Guest (May 2018)
The image features an endoscopist's view of a well-settled, obnoxious character, seated at the junction of the stomach and oesophagus.

A CT scanner, oncologist's apothecary of lotions and potions and surgeon's scalpel are all required for long-term eviction. The ethereally floating poison bottle shows chemotherapy as both a strong deterrent and cause of lingering side-effects (also see *State of Play*).

7. The Chamber of Closed Doors (April 2018)
The song *Chamber of 32 Doors* by the progressive rock band, Genesis, features a character stuck in a chamber in a parallel universe. Every door he goes through brings him back to the same place. This was how I saw myself when I was diagnosed and during treatment – there's no escape. I saw cancer references everywhere: online, on TV, in shops and public buildings. I heard the sound of personal doors slamming shut and was unsure whether some would ever reopen.

This drawing is about sinister unease, confusion and frustration but distant torches symbolise hope.



8. State of Play (May 2024)
Oesophageal cancer is tricky to treat, yet a range of treatment options exist and research continues to work towards finding and evaluating more. The above drawing captures the current ones.

The endoscope is used for both diagnosis and treatment (e.g. mucosal resection). The operating table is for surgery, both open and minimally invasive (keyhole). Antibodies on the wall are advances in immunotherapies. The windows on the doors show both radiotherapy and robotics. Robots are not yet in routine use but may not be far off.

9. If You're Going Through Hell (May 2019)
I had chemo at Christie Hospital in Manchester and my pet name for it was Hell, as they do horrible things to you there. However, during the process you're made as comfortable as possible, in pleasant surroundings. At every visit I'd encounter extraordinary people, who were extraordinarily lovely.

During a talk on the emotional challenges faced by oncologists, J William Eley, from Emory University, quoted his brother, who had undergone chemotherapy at his centre. He summed up this paradox really well, by describing the treatment centre as:

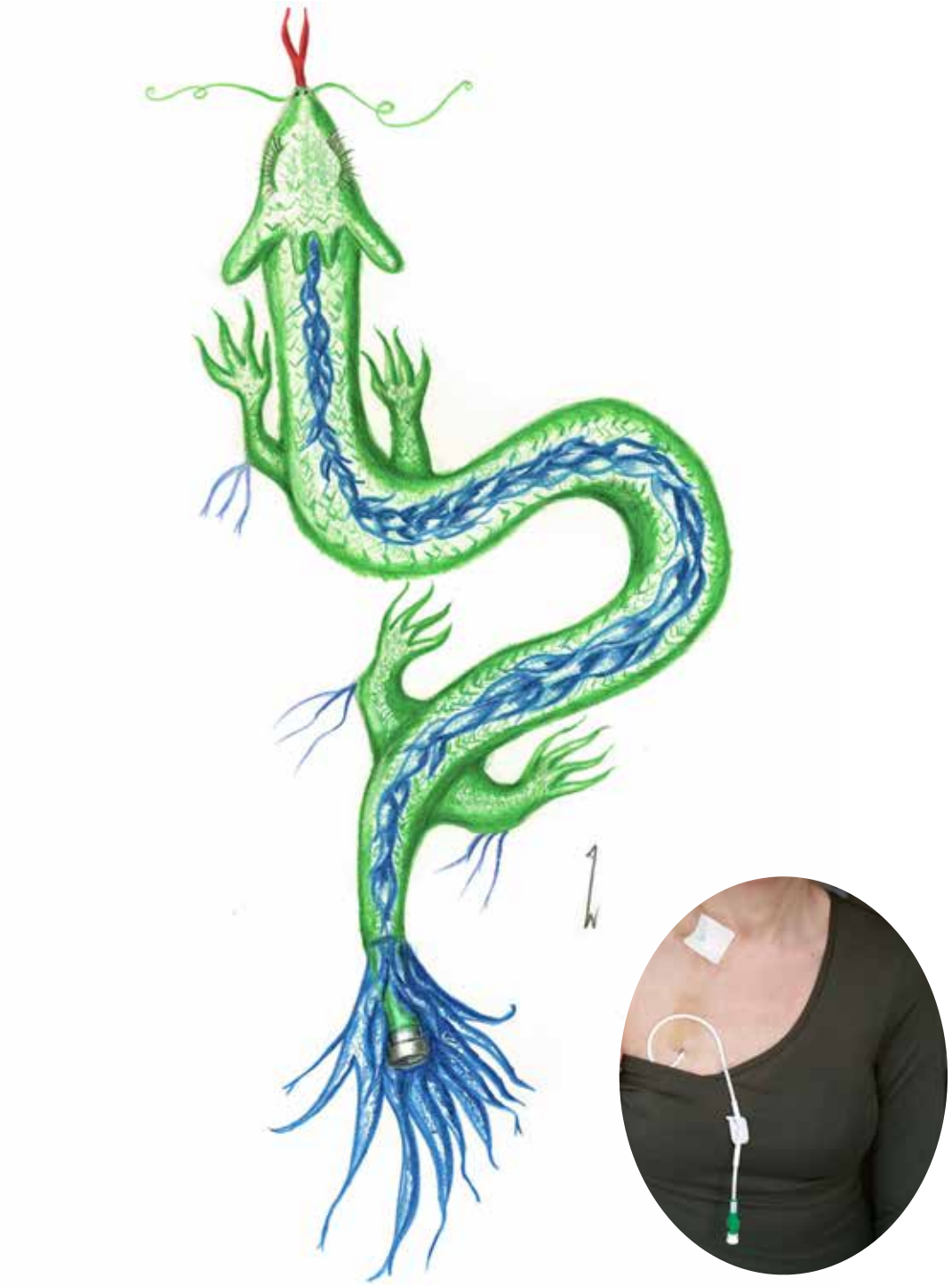
"an elegant torture chamber staffed by the kindest humans in the world".

10. Tethered (December 2019)
Tethered is a later, more reflective version of *If You're Going Through Hell*.

Here the Christie Hospital logo is fashioned as a balloon to represent random acts of kindness carried out by staff and patients, while sinister eyes show the scary side of treatment. The circus tent refers to the back-and-forth business of attending numerous appointments, alongside other people sharing a similar experience.

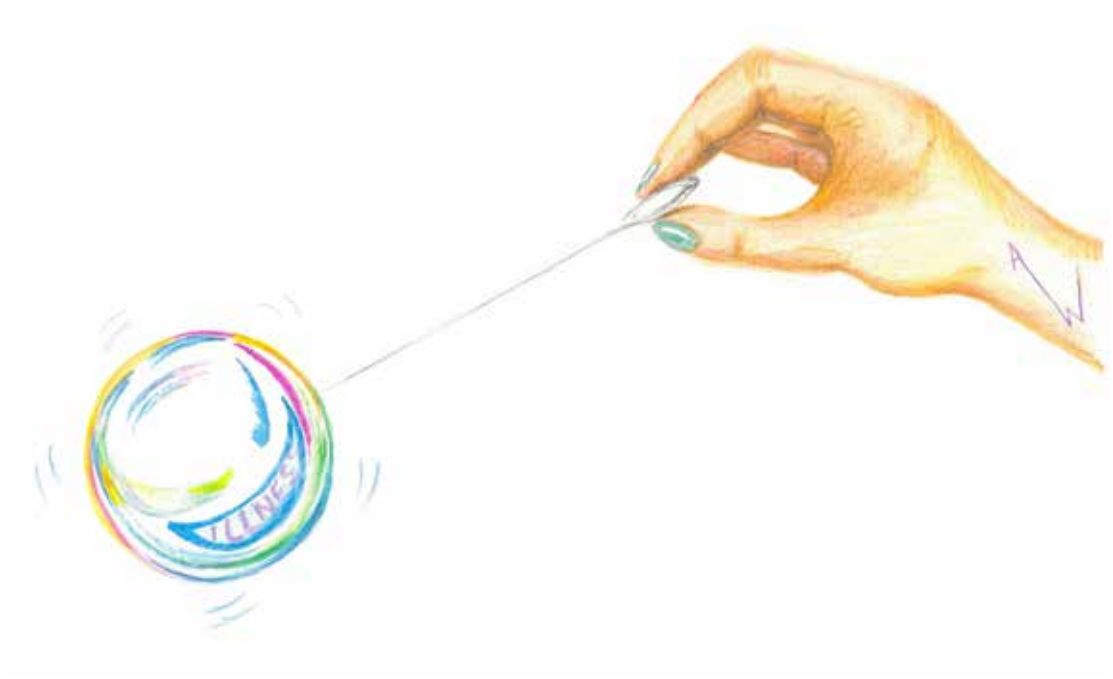
As a cancer patient, even when you're not undergoing treatment, you're advised to monitor your temperature and return to your cancer centre between treatments for blood tests. When out and about, you should be vigilant over hygiene, carrying out regular hand washing, limiting contact with others and avoiding certain foods. Months, even years, after chemotherapy has finished, one remains tethered to the memory which, although fading into the past, still remains a huge part of life, especially if side-effects linger on.

The numbers on the right of the volcano represent depth of tumour staging. This looks a long way but in reality, is only micrometres. The volcano is the site of the cancer, doubling as a kind of cross-sectional view of the junction of the oesophagus and the top of the stomach.



11. The Hickman Dragon (May 2018)
This image is inspired by the Hickman line, the venous catheter used to administer chemotherapy into the right side of the heart. It is a plastic tube where one end sits inside the chest and the other hangs outside the body, ending with a removable bung (see photo). It stays in place until treatment is complete to facilitate long drug infusions and the taking of blood samples. The tube is always looped to prevent catching and being accidentally dislodged. It is a risky yet extremely useful piece of kit that demands respect but only needs a daily shower, a weekly saline flush and a fresh bung after each use to keep it happy.

12. Hair Loss (April 2018)
I have mid-length hair and like others facing chemo, chose to have it cut short before treatment began. My hair started to shed significantly after the second cycle, starting slowly and then becoming too unstable to touch, let alone wash. I wanted to show this fragility and felt the resonant sound frequency of glass showed this perfectly as there is a shock factor attached to clumps of hair starting to fall out. The build up of sound was like the drug reaching a critical level in the body. Follicles are essentially put to sleep and can no longer hold on to hair shafts. However they slowly start to reawaken a few weeks after the final cycle of chemotherapy, one the drugs have cleared from the body. When hair grew back, I had thick and course 'chemo curls, like the fur of a fox terrier. Within a year, this had returned to a normal texture.



13. Bursting the Bubble of Illness (May 2018)
The end of chemotherapy is a time for celebration, with some patients enthusiastically ringing the 'end of treatment' bell in their chemo suite. I called this stage a reprieve from being in the bubble of illness. It signalled a period of rest and recovery ahead of surgery. I felt good at this point and started to exercise again to build stamina. Going back to work until the operation date also made life feel more normal and helped the time to pass.

14. The Run Up to 51 (May 2018)
Several of my close family members died in their 50s, so even before I was diagnosed, I felt a growing apprehension as I approached this new decade.

My surgery was to take place a few days before my 51st birthday and I wondered if I'd see it.
All surgery carries risk and I'd been told that 10% of oesophagectomy patients do not make it out of hospital.

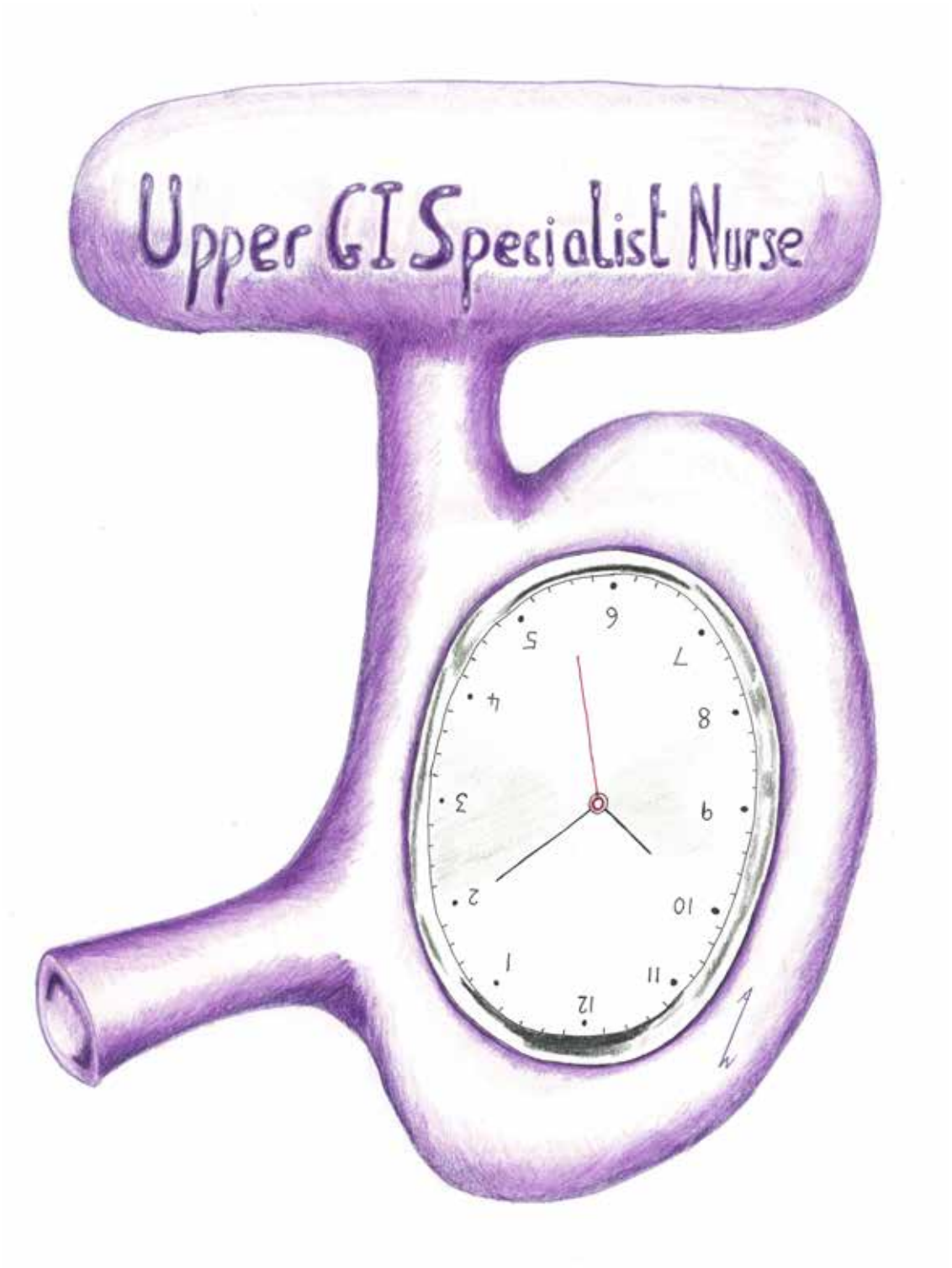
I drew the above the day after the 2018 London Marathon, and when I looked at the finished image, I found it quite chilling but I liked it too much to rip it up – it is definitely one of my favourites.

15. Wristbands (June 2018)
I love live music and am a regular concert-goer. Two days before my surgery, the very first *Warrington Neighbourhood Weekender* music festival was due to take place. I'd bought the tickets long before I'd developed any symptoms and was really looking forward to going.

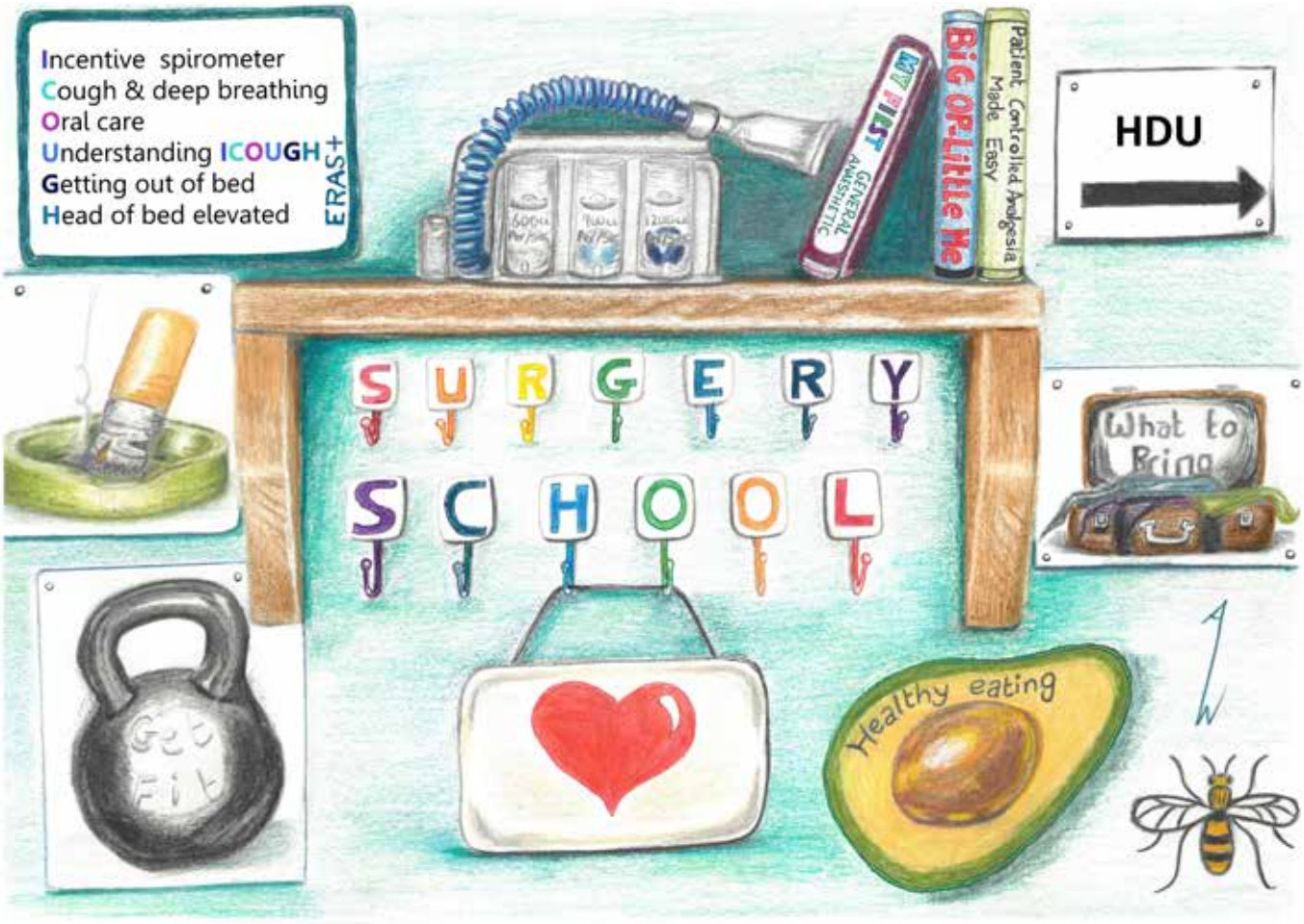
The drawing above shows a festival wristband being swapped for a hospital one. The hands represent a reassuring handover from my network of support and free-living self to an institutionalised self.

I only managed the Saturday in 2018, as I needed to conserve my energy for surgery. In 2019, my energy was much better so I attended both days. In 2020, *Weekender* was rescheduled to September 2021 due to Covid and in 2022 and 2023, it went ahead as planned.

There was a fallow year in 2024 and there is talk of a return in 2025. I'll always remember the first five with fondness and gratitude for being alive and able to be there.



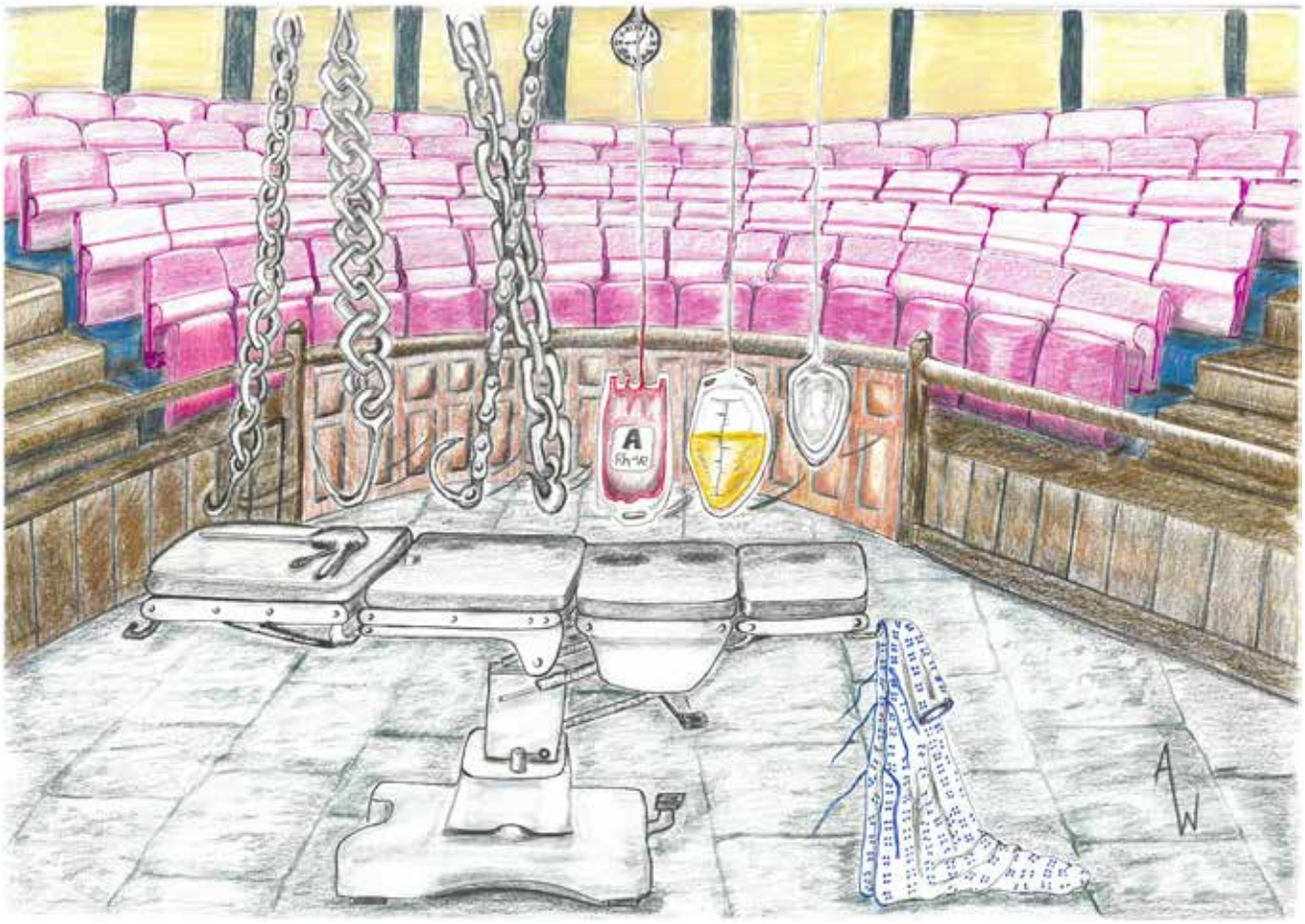
16. Fob Watch (September 2018)
This surreal variation on a nurse's fob watch, resembling a stomach, pays homage to upper gastrointestinal clinical specialist nurses, who support patients throughout treatment and beyond. They're wonderful and only a phone call or email away if you need them.



17. Surgery School (November 2019)
Surgery School is a critical care-run session, advising patients on how to prepare for major surgery. I wanted to showcase how lucky we are in Manchester to have this fantastic, patient-centred, evidence-based session. This took place about 5 weeks before my op day.

The meeting includes advice on diet and exercise, a visit to the High Dependency Unit (HDU) and receipt of an incentive spirometer (below) for use four times a day before surgery. This forms part of the ICOUGH Enhanced Recovery After Surgery (ERAS) scheme, researched and developed by a collaboration of Critical Care Teams at Central Manchester Foundation University Hospitals and Boston Medical Center in the USA. Chest infections post surgery are a common complication and the ICOUGH protocol helps patients to help themselves. The incentive spirometer can be taken away and used at home to improve lung capacity and breathing efficiency, during the weeks before surgery. Patients are then encouraged by physiotherapists in HDU to cough and use a spirometer to help keep lungs clear.

More and more hospitals are offering similar prehab sessions but not all offer incentive spirometers. You can, however, buy them online.



18. Hell-raising Surgery (October 2019)
The image captures the loneliness and vulnerability felt by the surgical patient, dressed only in a thin hospital gown while surrounded by lots of strangers.

Being told my op would be keyhole, and would involve a number of incisions, made me think of the horror film *Hellraiser*. I don't recommend you watch the film but suffice to say, it features a room with hanging hooks to rip victims apart.

Above shows the scene is set for the operation, complete with the backdrop of an anatomy theatre, equipment and hospital gown. The idea for the magenta-coloured seating came from the Royal Institution in London. I have loved this place since watching the Christmas lectures as a child.

There are not enough seats visible for the large number of NHS professionals who had a role in my care, i.e. endoscopists, nurses, radiographers, dietitians, physiotherapists, oncology and surgical teams, receptionists and catering staff.

Surgery is like legalised assault and feels very surreal. Your surgeon tells you they'll inflict grievous bodily harm on you and you might die. You sign a form to say 'OK' and one or two people do the wounding, while an entire team of individuals watch carefully to ensure you do not feel a thing. Then another team gets you well and continues to check your progress several months/years later.

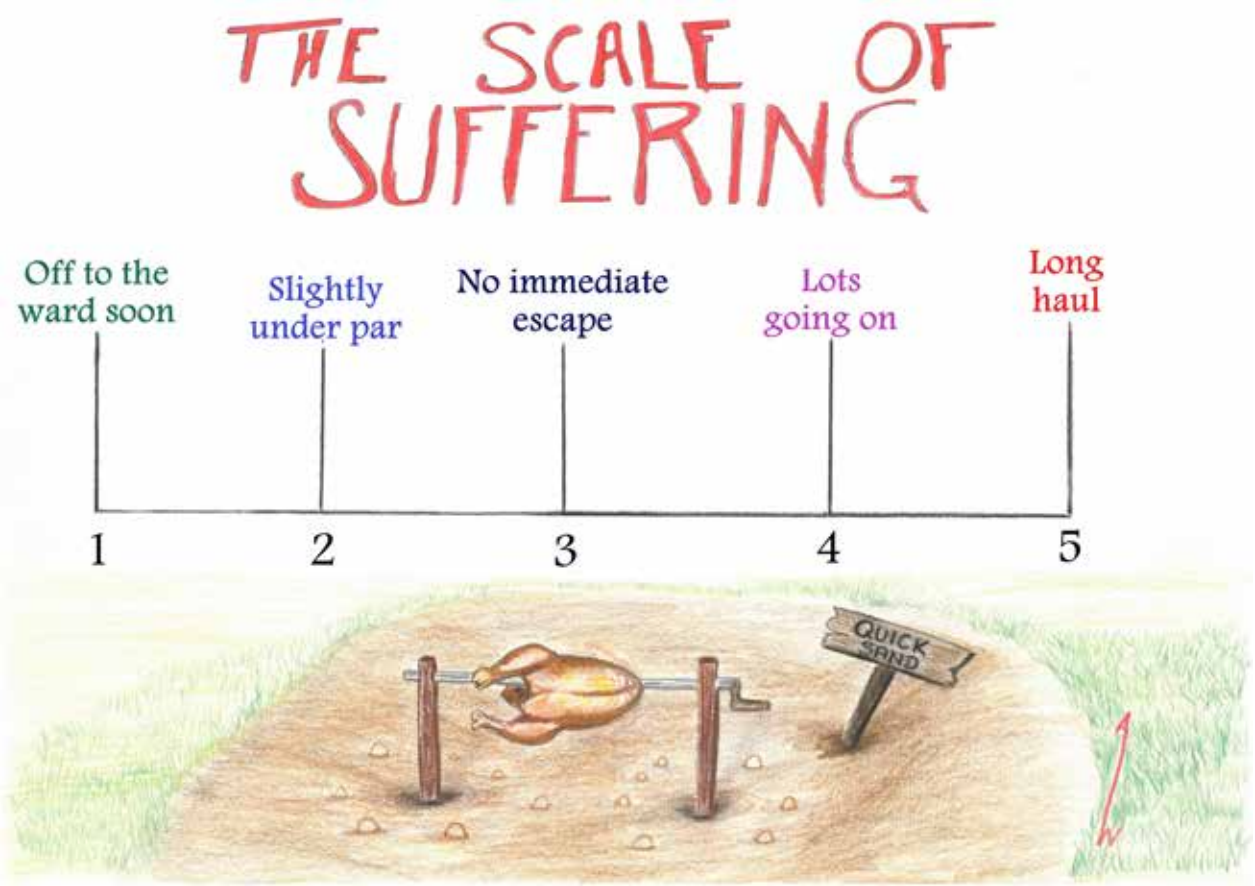
19. Incarceration (November 2019)
This is about loss of liberty on the High Dependency Unit (HDU). This was my first surgical inpatient and HDU stay and before I went in, I had no notion of how hard it would be being holed up there for several days. I'm not the most patient person but I expected to be in a drug-induced stupor so time would pass relatively quickly. Instead, I felt mentally sharp, making being locked in all the more difficult.

In the background on the left is Manchester city centre. However, the inspiration for the main HDU block came after a visit to Crumlin Road Gaol, in October 2019, on a city break to Belfast.

Also on the left is a cactus garden to show extreme thirst, due to being 'Nil by mouth' for 1 – 2 days while everything healed up. I was thankful for the lovely HDU nurses who brought me heavenly water-soaked, foam sponges, to freshen the palate.

Healthcare is heavy on resources of all kinds and even through the fug of post-anaesthesia and pain meds, I noticed high levels of consumables being used. The main ones were vomit bowls, lengths of tubing, huge drain buckets and daily changes to bed linen and gowns. This gave me the idea for underground storage rooms to add some depth to the picture.

Once on the ward and more mobile, I started to explore and sought out somewhere to sit to enjoy the uncharacteristic heatwave Manchester was having at the time. If hospital grounds are made too pleasant, people would never want to leave but there is a balance. Where I was, the green areas were locked so you could not gain access to simply sit in them. I felt like Alice in Wonderland when she couldn't gain access to the garden. Instead, I had to slowly pace up and down the hot corridors, feeling and probably looking wraith-like and alarming passers-by.



20. The Scale of Suffering (July 2018)
Being on HDU is a very humbling experience. Everyone is on the scale of suffering and this is a tough watch when you're somewhere in the middle. My heart went out to those on 4 or 5.

I remember all my neighbours, particularly someone brought in after a road traffic accident. I felt so sorry for this person as they'd probably started their day with big plans and intended to be home in time for dinner. Instead, they ended up in hospital, miles from home, unaware of how they'd got there and suddenly having to be helped in and out of bed. I was thankful I'd been allowed to walk down to theatre so I knew where I was and how I'd landed there.

HDU beds themselves also add another level of lived experience. The mattresses were as soft as quicksand, making it impossible to get any purchase to move around, let alone escape. Mobility was hindered not just by all the tubing but the epidural blocked nerves to the core abdominal muscles, which felt like wearing a corset of wood. It is surprising how much core muscles are needed for pretty much every movement. The mattresses used are 'anti-pressure sore' and inflated and deflated automatically, so nursing staff do not need to lift or turn people. These ongoing cycles rock you ever so slowly back and forth like a rotisserie chicken, with a rhythmic gaseous accompaniment.

21. Torn Between Two Medics (July 2024)
Anyone who has come across videos by @DrGlaucomflecken (AKA American ophthalmologist, Will Flanary) knows doctors can have different points of view, especially surgeons and physicians.

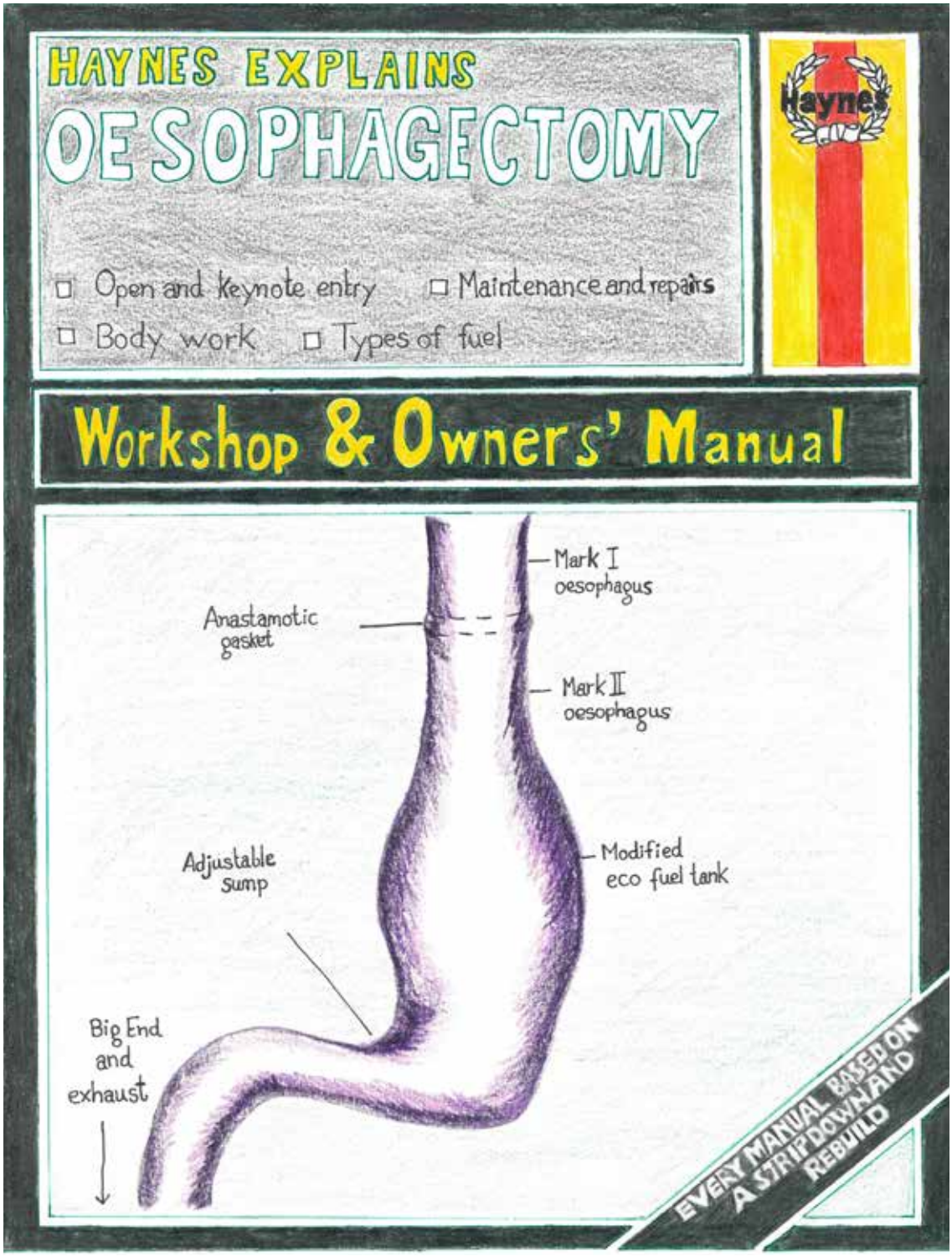
I'm not having a go at doctors here - quite the opposite in fact. It's important for patients to realise, medicine is not an exact science and professional debate is both healthy and vital for securing the best outcomes. However, as a patient, these debates can get played out in front of you. Be aware it can happen but don't let it worry or alarm you.

The treatment for oesophageal cancer is brutal and the bulk of it has to be 'done to you', leaving you with very little control. Having a say in your care minimises the feeling of being swallowed up by the process. Listen to options and what may happen with each and go with what feels right for you.

You will be consulted about aspects of your care and if well enough, you can choose to simply smile and nod and say 'You know best' or make a solid, informed contribution. If you're not well enough, hopefully a family member, friend or carer will step in and be your advocate.

I personally like loads of information and would have loved a copy of my care plan. I could then have understood the hoops to be jumped through to get out of hospital and return home, to recover at my own pace.

The screen above the patient gives a 'bemusement reading' as well as vitals like heart rate, oxygen saturation and respiration rate. The beanstalk above shows health and growth. 'Mission Control' refers to the nurses' station. Through the window above is the outside world. As a patient, you often forget the universe still exists beyond the confines of your hospital bed.

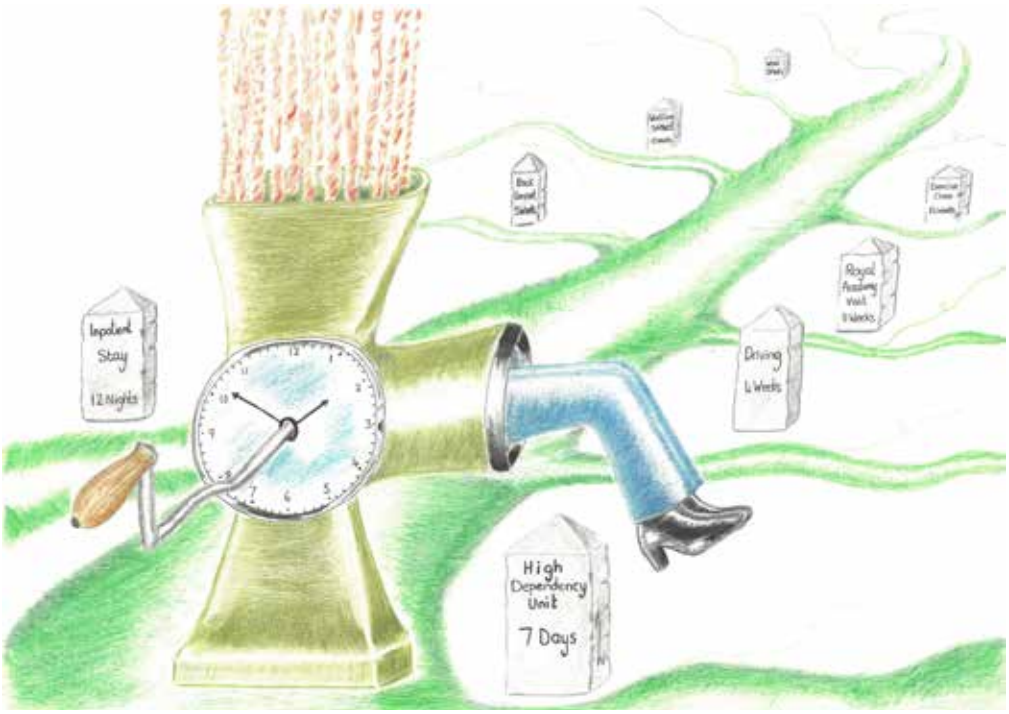


22. Haynes Explains Oesophagectomy (August 2018)

Anyone who has attempted to understand the workings of their car may have read or owned a Haynes manual. After oesophagectomy, your stomach has been reconfigured and you have to learn how to eat again. Support and guidance is on hand but a personal manual would have been really handy, especially one listing the right foods to eat, in what quantities and how to trouble-shoot symptoms. Instead, each food and portion size has to be tentatively tried and tested until it yields the most comfortable result. A food diary definitely helps and if you have the know-how, a spreadsheet to log quantity, effect and nutritional value can help to quickly spot patterns emerging.

23. Normality (August 2018)

Around 9 weeks post op, I was longing for some semblance of normality. In the above, I'm the train wreck (or to quote a good friend, a derailment). The road to the left is my recovery. At this point, I felt I was two-thirds of the way up but still had a few obstacles to negotiate - one being a ruined tower representing the psychological side of cancer. You can get stuck in here, dodging the falling masonry. On the right is the reminder of recurrence, symbolised by the sword of Damocles and a green mile. *The Green Mile* refers to Stephen King's book (and film) about a group of prisoners on death row in the 1930s. At this point, the future was very unsure. *Normality Revisited* has a vibrant background and is a more hopeful version of *Normality*.



24. Milestones (December 2018)

After such a massive operation, you do feel you've been through the mill a bit. The reverse mincer represents wound healing and getting back to normal activity after five incisions, three chest drains, one feeding tube and a broken rib. The eight milestones above show progress up a mythical beanstalk to symbolise health, growth and strength. This stops at a return to work at 6 months but in reality, recovery and learning how to adapt extended beyond this time.

25. Weight Loss (August 2018)

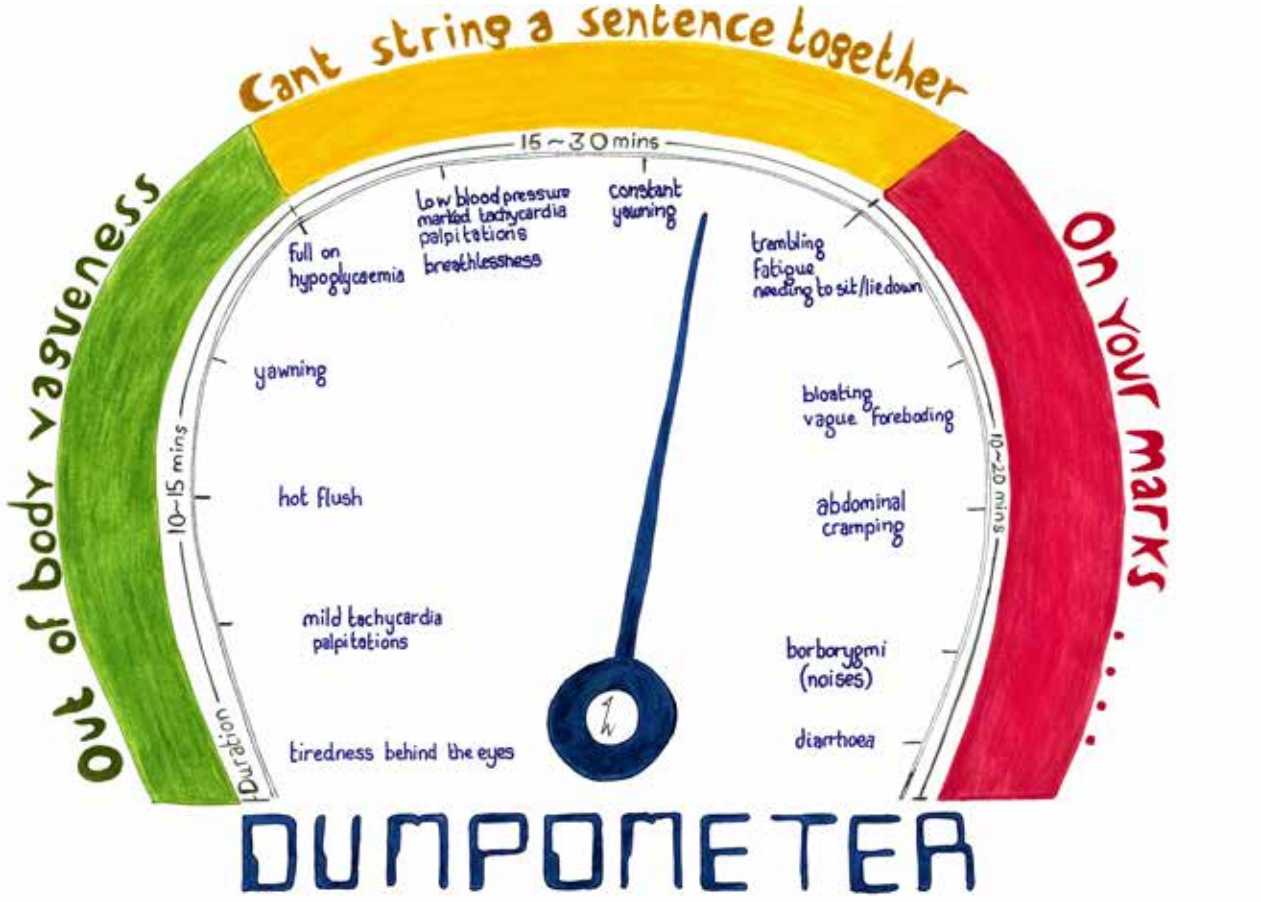
Like bariatric surgery, oesophagectomy causes weight loss due to reduced stomach size. With a third of the stomach gone, eating smaller portions by the clock is the way forward. I've always been slim and never had a huge appetite, so the expected 10% weight loss was a worry. I bulked up as much as I could before surgery and for at least 18 months after, indulged in a bit of childhood nostalgia having Ready Brek for breakfast. This smooth porridge was marketed as 'central heating for kids' because it is served hot and fortified with iron, B12 and vitamin D. I blended it with full fat milk, laced with Marvel to add more calories, and it was delicious. My weight stabilised around four months post op but it took about a year to feel confident about food types and portion sizes.

26. A New Way of Eating (March 2024)

I love a nice cafe and ate out quite a bit during the first few months after surgery. I stuck to starters or shared a main course and was not afraid to ask for a doggy bag for leftovers. I used side plates rather than dinner plates to judge portion size and still do as this avoids feeling over-faced.

My golden rules for comfy digestion and avoiding dumping syndrome (see *Dump-o-meter*) are:

- eat little and often
- avoid drinks during or immediately after meals
- chew well, and
- avoid rapidly digestible, soft and liquid forms of sugar, such as in cake icing and sugary drinks.



27. Dump-o-Meter (December 2019)
This describes my dumping syndrome experience in terms of a red, amber and green scale. Although common after any gastrointestinal surgery, it is a given after oesophagectomy. There are early and late forms but my worst experiences were triphasic and when it occurred during the months after surgery, it came on within minutes of eating.

Dumping syndrome is a form of reactive hypoglycaemia and incredibly unpleasant, even in its mildest form. Some people counteract the effects by eating something sweet, whereas I prefer to ride it out by sitting quietly and breathing deeply. I find eating sweet foods make me crave them all the more, allowing the cycle to continue. It's a personal choice.

The 'green' phase occurred most frequently and mostly did not progress. I can function in 'green' as the heart rate is only slightly raised and it is accompanied by a mild, zoned-out feeling. Progression from 'green' to 'amber' renders you unable to string a sentence together. You also get tremors, sweats and a racing heart rate, which feels grim. It takes about 15 – 20 minutes to pass off.

'Amber' often progressed to 'red' in the weeks immediately after surgery and made life unpredictable. This improved massively after 3 months onwards and 'red' is extremely rare now.

Triggers include eating/drinking too much/too quickly particularly following a long interval between meals. For the first year, simply eating breakfast sent me frequently into 'amber' and if driving anywhere, I'd have to wait for it to pass off. Sugar/starchy carbohydrates are definite triggers. Eating fruit and veg, even as a smoothie, has never been a problem for me but can be for others.

To avoid problematic dumping, avoid eating fast-acting carbs and eat very sweet foods with caution. As mentioned, avoid fluids straight after food and even when drinking between meals, take it slow. The nerves controlling stomach emptying have been cut so liquids flow freely and can easily carry semi-solid food down into the small intestine – rather like flushing the loo or unblocking a drain (see also *Dam*).

28. Stretch (June 2024)
Gluggle jugs were popular in the 19th century due to the swallowing sound they make when in use. An oversized strawberry hovering above one of these iconic jugs epitomises swallowing difficulties. This is an important red flag for oesophageal cancer and should never be ignored.

Swallowing difficulties can also occur during the weeks after surgery. As it heals, a narrowing or stricture can form at the join between the remaining oesophagus and stomach (anastomosis). If more and more foods start to get stuck, you should let your specialist nurse know. You'll first get a referral for a 'barium swallow' – a delightful little procedure, where you drink a white, chalky liquid, under X-ray control, while positioned at different angles. Any obvious narrowing will show up and should prompt a referral for a dilatation or 'stretch'.

I first became aware I might need a stretch after eating a humble strawberry. Even when you think you've chewed them well, they can be solid, little beasts. Anything getting stuck at this stage was neither pretty nor pleasant as it results in the endless coughing up of copious amounts of mucus (my daughter referred to this a 'cough-a-thon'). A stretch soon resolved this problem. It's carried out using a special balloon that is gently inflated via an endoscope to widen the aperture of the new oesophagus. Some people may need a repeat but I was fine after one.

I couldn't eat strawberries or raspberries comfortably for about a year and tended to blend them. I rarely have issues now unless they are particularly solid and bumpy.

29. Watertight (June 2024)
The skin is the largest organ in the body and keeps the body watertight. If the skin is breached, this leaves the internal environment vulnerable to infection. Treatment for oesophageal cancer involves numerous breaches over several months. First is a cannula for chemo (*Hickman Dragon*), then as that heals, numerous holes are needed for scan dyes, blood monitoring, surgical lines, incisions and chest drains. The last breach to heal was the hole left behind from a jejunostomy ('jej' or j-tube – see photo).

A 'jej' or j-tube is a feeding tube to maintain nutrition and bodyweight after surgery. Not every surgeon is a fan as j-tubes can come with complications. The tube is temporarily sewn into your abdomen and during the day and before sleep, you set the controls of a pump to deliver a fixed quantity of revolting, brown liquid through this tube and into the small intestine (jejunum). J-tubes can be life savers and I'm glad I had one but they are the stuff of nightmares. I cannot describe the sheer relief I felt when it was taken out and I was watertight again and another step closer to normality.

The holes in the barrel above correspond to the holes in the abdomen made during surgery. The barrel revisits the concept mentioned in *Scale of Suffering,* where core muscles felt like a wooden corset. Nerve damage under the right-hand rib cage may result from incisions or a rib being broken in the back of the chest. Either way, it was incredibly sensitive and painful for about 3 months after surgery and even now, that small section of skin still feels kind of alien, in an odd and tingly way.

The length of garden hose under the barrel represents all manner of tubing required during treatment, regardless of form, function or location.

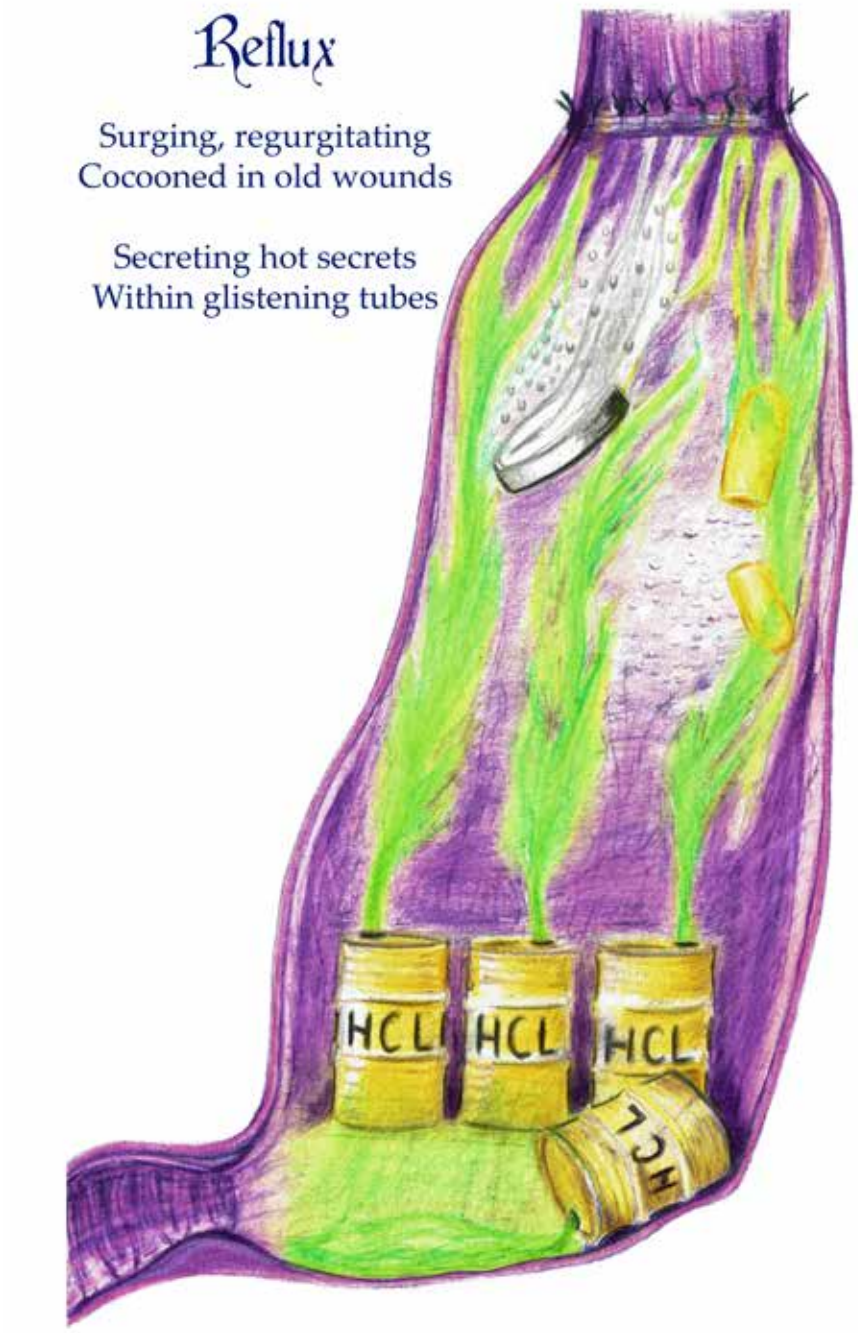
30. The Trouble with Omeprazole (May 2018)
The next three drawings are about reflux and acid control.

Some oesophagectomy patients are not bothered by acid but I get flare ups. This in turn can kick off the infamous 'post-oesophagectomy cough' referred to in *Stretch*. Be prepared to endure many exhausting cough-a-thons in the weeks following surgery. Even now, coughing can be triggered by chunky or spicy foods (e.g. oats, apples, meat, chilli) or by a sudden inhalation or laughter.

The image above represents my extreme dislike of having to take omeprazole, an acid-reducing drug called a proton pump inhibitor (PPI). There is some ambiguity over their long-term safety so having to take these for life is a necessary evil. Some studies suggest a link to dementia while others don't. There's also evidence in the literature suggesting a link to osteoporosis and hypomagnesaemia. I know people of advancing years, who've taken PPIs long-term with no issues. Still, it would be handy to know the true picture around safety!

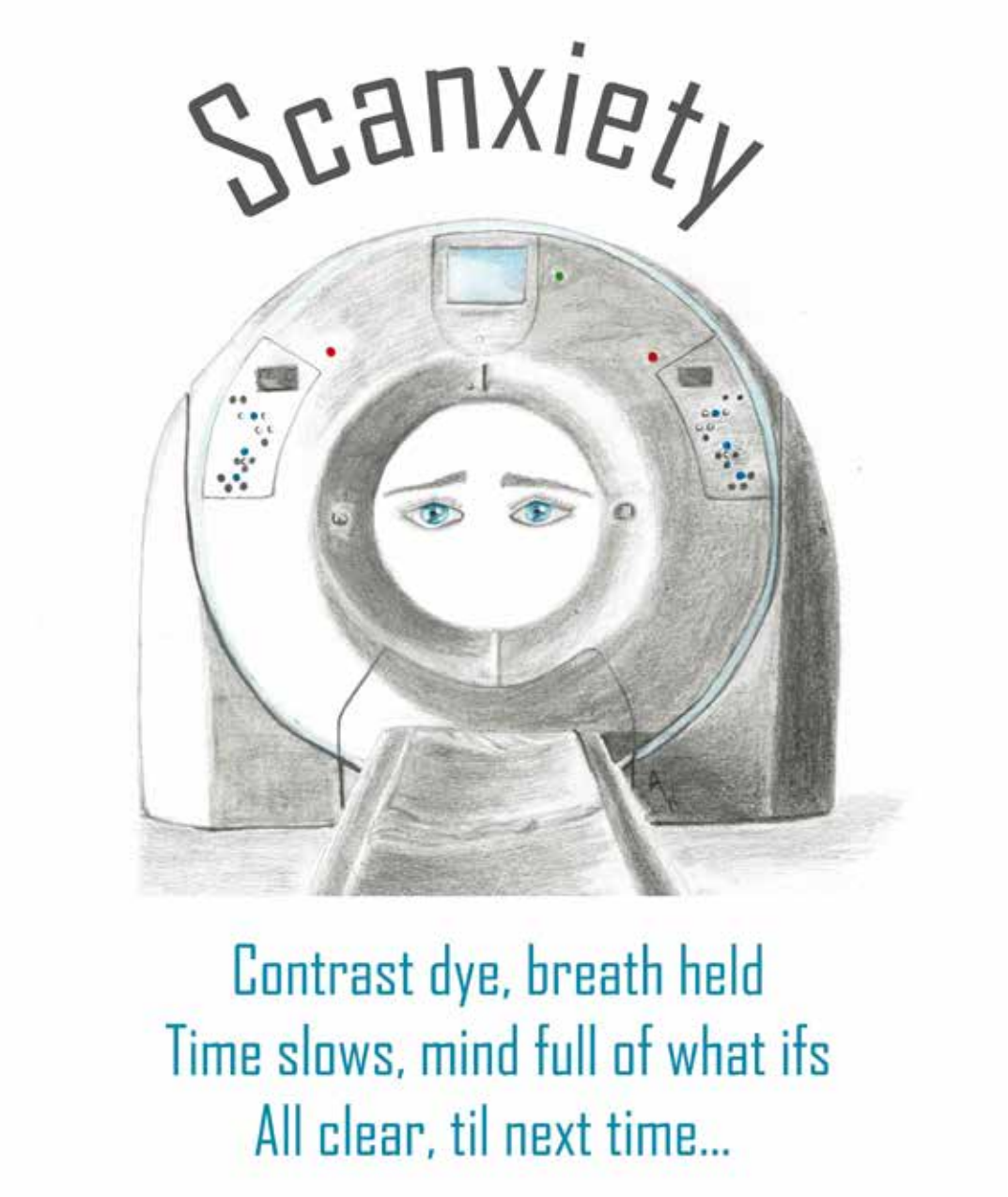
31. For the Love of Alginate (December 2019)
The image above is about discovering something is an integral part of your life when previously, you'd never heard of it. This was the case for me with alginate, a natural gel-like substance with remarkable uses that is extracted from kelp. It is the key component in modern over-the-counter antacids such as Gaviscon. On contact with gastric secretions, alginate forms a protective barrier between the acidic contents of the stomach and the oesophagus. As I'm now prone to acid reflux, I always carry Gaviscon Advance in my bag and have a pot next to the bed. Every month, I get through a 60-lozenge-pot, usually needing 1-2 during the night.

Alginate also forms part of some dressings and acts as a poultice to absorb fluid from wounds. I found alginate dressings really useful in hastening the healing of the wound left after my feeding tube was removed. I've gone from knowing nothing of alginate to fondly regarding it as a natural treasure.



32. Reflux (October 2021)
I started to write creatively in 2021 and joined a number of virtual workshops during the Covid pandemic. Images 32 and 33 are illustrated poems created for the *Art of Oesophageal Cancer* exhibition, in Manchester Central Library from January to March 2022.

The image and verse above refers to the ongoing issue of reflux and shows omeprazole and an antacid lozenge sinking downwards, attempting to neutralise the acid rising upwards from containers posing like dumped chemical drums on the seabed.



33. Scanxiety (June 2024)
The above is an illustrated haiku. Haikus are a Japanese form of poetry and constrained writing, with 17 syllables running over three lines in a 5:7:5 syllable pattern. They are usually about intense human moments, relating to beauty and nature. I thought I'd go for something a bit different.

Scanxiety is something all too familiar to any cancer patient regardless of tumour type. It relates to the worry and anxiety over having, and waiting for the results of, a significant medical test. This is usually a scan but can include any diagnostic, from blood test to endoscopy.

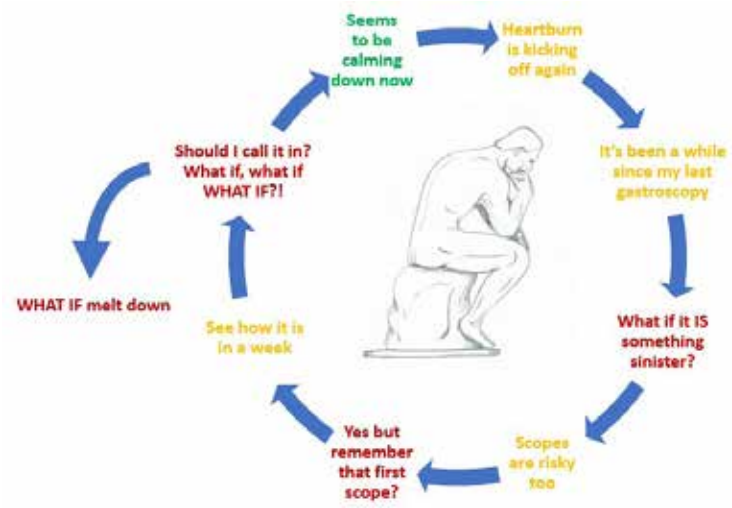
You just keep everything crossed hoping the test comes back clear.

34. The Wobble (March 2019)

Like *Scanxiety*, *The Wobble* relates to the psychological impact of cancer, loss of confidence with life and current and future health. It is definitely the darker side of cancer, as after diagnosis you can easily find yourself taken hostage by symptoms. Surgery leaves you with scars, nerve damage and a reconfigured digestive system, resulting in a plethora of new sensations. Acid reflux remains an ongoing challenge.

The image above shows a skeletal sniper, whose aim alternates between me and a see-saw. This symbol shows the balance between normal and mutated cells. During a wobble, a blue sky is obscured by a brick wall and I'm trapped between a rock and a hard place. It's a grim image, showing a mind in torment but surprisingly, it helped me come to terms with living with peril.

35. The Wobble Cycle (February 2024)



During a wobble cycle, inner voices react to new symptoms by gently instilling a fear of recurrence. Opposite shows the escalation to a frenzy of 'What if?' conversations, needing strong self-management or external support. Wobbles are horrible but it's also helpful to notice and acknowledge when you're in one, so you can seek help. I had my first major wobble after a bad flare-up of acid, about 9 months after surgery, and have had a few since.

Specialist nurses are brilliant if you need reassurance but if it has gone beyond this and there are concerning symptoms, they will refer you for tests.

As time goes on, wobbles get fewer and further between but uncertainty is always there. To quote a friend of mine, who is also a former cancer patient,

'With cancer, if there is one thing you can be certain of, it is uncertainty'.

36. A New Way of Sleeping (October 2021)
Sleep is a basic human need and arguably the best medicine for getting over illness. However, getting comfortable enough to get quality sleep after oesophagectomy can be a challenge as you are advised to sleep more upright.

Sleeping upright may seem a big ask but the ICOUGH protocol (mentioned in *Surgery School*) gives patients ample opportunity to try it out in hospital. Once you're home, that is where the fun experiments begin. During the first few weeks, my bed was propped up like in the picture above but it didn't take long to get fed up with constantly sliding down. With the bed on the flat again, I found strategically placing five or six firm pillows on top of a foam wedge, then placing a firm pillow under the bottom, worked really well.

Some people prefer to invest in an adjustable bed but these can be expensive and you can't take them on holiday. Needing only a few pillows to prop yourself up is really handy if you have a penchant for travel. If you're in your a car, you can take ones from home. When travelling by other means, a simple request for more pillows when you book or on arrival works well. Hotels offering extra pillows on their booking forms makes life easier. Failing that, wrapping a quilt tightly around yourself also keeps you in one place.

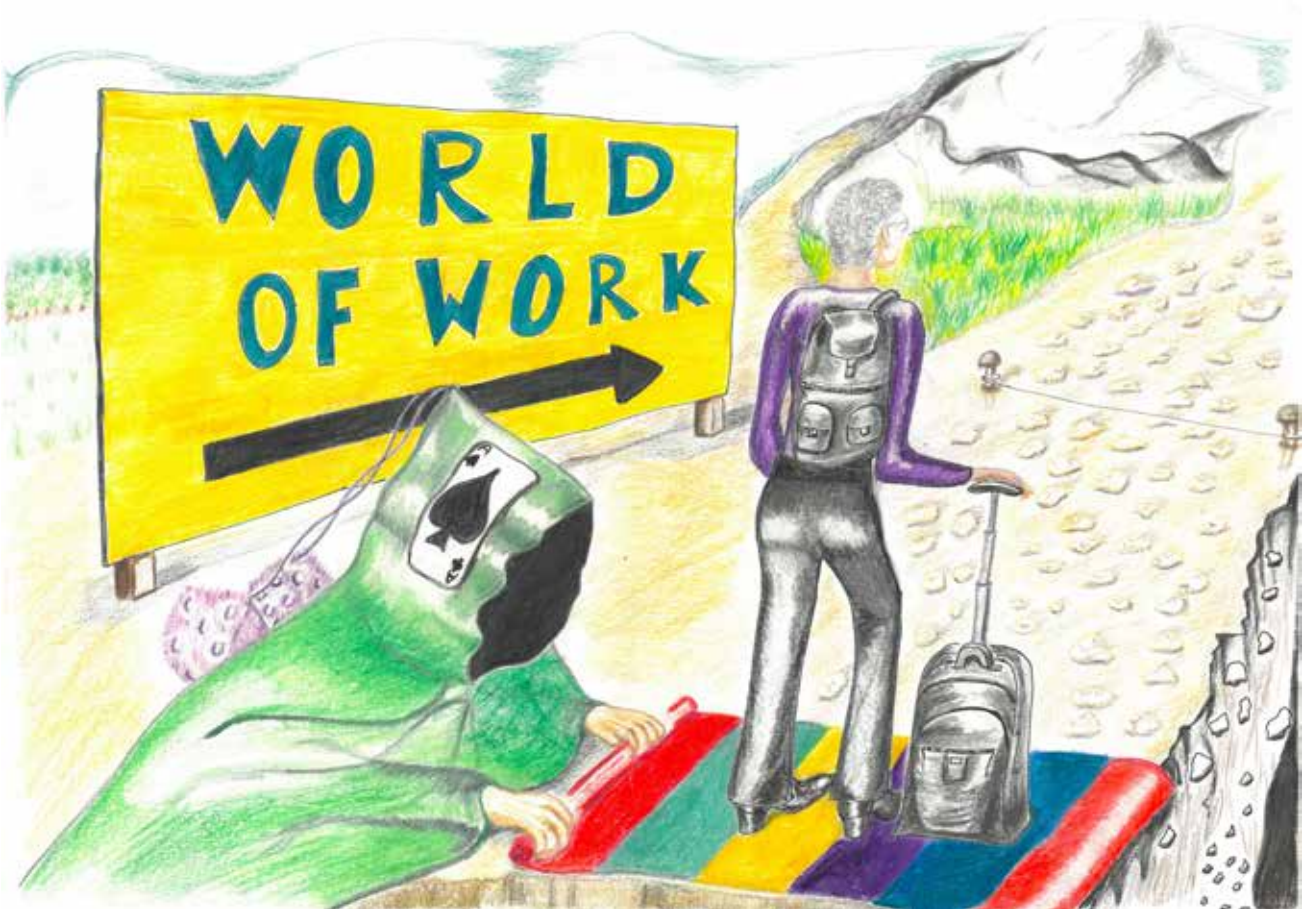
After surgery, you may also find you can only sleep on one side – my preferred side was always the right and thankfully this was unaffected. I can't sleep on the left without feeling really off. It's a weird thing and I can only describe it as a pressure in the upper abdomen that usually leads to reflux.

I miss being able to lie flat, especially if I want a cheeky nap. I used to love yoga, pilates and massages but all of these cause me issues now. I can usually find workarounds for the things I really want to do and, on the whole, life is good and far better than the alternative.

37. The Princess and the Spices (November 2020)
This was drawn for *Oesophageal Cancer Awareness Month* in February 2021. It is based on the story of *The Princess and the Pea* and is about another personal legacy of surgery.

I'm able to detect the smallest quantities of some spices in foods, as they sting my oesophagus, the main one being chilli. If you've ever chopped up a chilli, then accidentally rubbed your eye, the effect is really something. A similar thing happens within the oesophagus. To a lesser degree this occurs with pepper, vinegar, ginger, mint and citrus fruits, resulting in discomfort and coughing. I assume these effects are due to residual sensitivity or nerve damage in the oesophagus. I can tolerate these ingredients better now but still tend to gravitate towards less spicy foods.

The huge pile of mattresses is a nod to unconventional sleeping arrangements referred to in *A New Way of Sleeping*.



38. World of Work (December 2018)
It is a big deal going back to work after a long period of illness, especially when cancer was the reason behind the absence. A successful transition back into work can be achieved with an understanding, flexible employer, willing to offer lighter duties, phased returns and freedom to take flexible mealtimes. I was lucky to have all these factors and a job I loved. I was determined to try to go back after 6 months but was not sure whether Fate might pull the rug on my plans. I've been lucky so far.

39. Normality Revisited (October 2021)
At the first consultation, my surgeon told me to write off a year. It did indeed take this long to get back to feeling relatively normal. Some people may need longer and that's fine.

The above is based on the earlier drawing, *Normality*, but with more colour in its cheeks. The ideas in the background represent travel and a general ability to get out more and enjoy life!

The train wreck is a life-changing event with the coal representing loss. Although you can recover aspects of your life, it will never be quite the same and may leave a bit of a stain.

The green hill represents good health and the 'No Entry' sign shows you cannot walk straight back in through the gate. Recovery takes effort, patience and the support of others and is via a steep climb up the ladder and an ascent up a rocky face, which admittedly does get easier towards the top. By reaching the top, you have proved yourself physically but then have to get over a flimsy, rope bridge across to a haunted folly to sort your head out. There's an easier descent but the tower remains a reminder, looking out over the lushness of better health.

The tower on the right is the Wallace Monument and was included after a solo visit to Stirling in 2021.

The setting sun and *carpe diem* (seize the day) graffiti are reminders that you never know how much time you have, so live your best life and don't put off the special things. A walk along the waterway on the lower right shows freedom to live a narrower yet still fulfilling life.

40. Chemo Fingers (February 2024)
This is one of several new sketches to mark living beyond the NHS follow-up of five years.

I found the prospect of chemotherapy far scarier than surgery due to its unpredictable and potentially toxic effects. Chemotherapy poisons the tumour but also poisons healthy areas of the body. It's a fine balance and is why oncology is a bit of a dark art.

All you have to go on are leaflets and the anecdotal evidence of how other patients got on. You will be affected in some way but hopefully you'll come through it and side-effects won't hang around too long and affect longer-term quality of life.

My chemo was known as FLOT, named after four of its five components:
Fluorouracil, **L**eucovorin, **O**xaliplatin, doce**T**axel and dexamethasone.

The platinum in oxaliplatin settles like dust in peripheral nerve endings, especially in the fingers and toes, making them super sensitive to cold. Six years on, I still find holding chilled or frozen objects really painful, even for a few seconds.

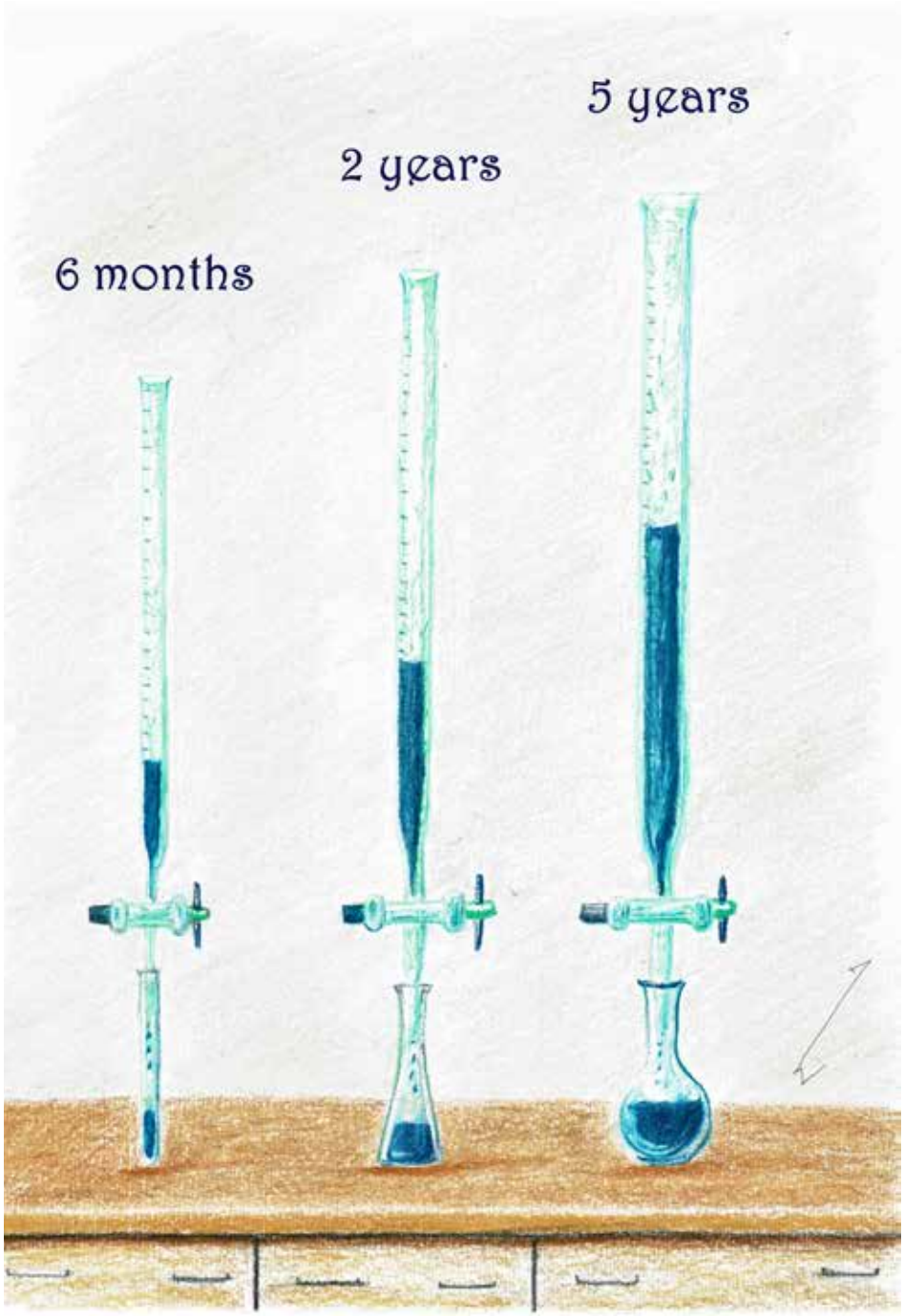
Compared with some people I've spoken to, I got off pretty lightly in terms of neuropathy. Needing to wear socks and gloves except in high summer is a small price to pay.

41. Big Bad Barry (May 2024)
This was drawn for World Barrett's Day on 16 May 2024.

The name 'Big Bad Barry' is inspired by a fearful fish character featured in the delightful children's animated TV series, *Ben and Holly's Little Kingdom*. The fiery colours on the fish and the red around the base depict the presence of acid and structural change induced by long-term exposure.

Like the cover picture, this drawing uses a Gluggle jug to represent the oesophagus. The black object above is a Cytosponge™ being pulled out. This promising diagnostic technique, mentioned under *Race Against Time,* was developed by Cambridge University as a non-invasive way to pre-screen patients for Barrett's oesophagus. The patient swallows the sponge in a capsule attached to a string. As the capsule dissolves, the sponge is released and expands. It is then drawn back up and on its way, picks up cells from inside the oesophagus. Any abnormal cells on the sponge can be detected by staining and viewed under a microscope. The patient can then be referred for the more invasive procedure of endoscopy to confirm the diagnosis.

In April 2024, I was diagnosed with low-risk Barrett's. This came as a major disappointment as I thought my acid control had been good. This diagnosis brings with it another layer of uncertainty.



42. Burette's Oesophagus (August 2023)

A burette is a piece of laboratory equipment made of glass, with gradation lines up the side and a tap at the bottom to control the release of measured quantities of liquids.

This drawing is all about how the stomach gradually increases in size over time. It is due to a slow 'drip, drip' process of the stomach wall adapting to increasing portion sizes. Changes are shown above at 6 months, 2 years and 5 years. I realised this was happening as, for several years, I'd stay in a retreat where we were given delicious, home-cooked meals. I was finding each year, I was able to eat a little more.

A return to eating full adult portions is unlikely but it's possible to eat enough to stay healthy and well nourished. Having said that, it is worth monitoring iron, B12 and other nutrients.

43. Dam (June 2024)
This drawing is all about the difficulty some people may have maintaining optimum levels of nutrients after surgery. This can be due to:

- lower digestive juice/enzyme production after partial removal of the stomach and nerves, leading to reduced breakdown and absorption of certain foods
- faster transit through the gut so less time for effective digestion, breakdown and absorption
- medications like omeprazole and antacids blocking digestion and nutrient uptake.

Dam is inspired by the science fiction film *Fantastic Voyage* from 1966, where a group of scientists are miniaturised to go inside someone to repair a brain clot. It's a great film. In terms of the above, picture if you can, standing in the foreground. This cavity represents the lumen of the duodenum – the section of the gut joining the stomach to the small intestine. Contents of the stomach gently filter through the dam in the upper left corner. There are no nerves now to control gastric emptying, so the flow rate depends on volume and gravity. The dam has 'omeprazole' graffitied across as this drug can hinder the breakdown of vitamin B12 and iron (Fe), which can be seen trapped in the outlet gates.

In the centre is an outlet pipe, through which bile and pancreatic juices enter in response to the arrival of partially digested food. The yellow globules are undigested fat that can cause some people to have 'steatorrhea', resulting in greasy stools further downstream. On the right are two villi, where broken down food is absorbed into the blood-stream through the central lacteals but unfortunately, here the levels in both fall short of the full height. I remember drawing a villus at school for 'O' Level Biology and to me it looked like a glass-covered fantasy kingdom.

The picture also shows the point where dumping syndrome begins. Excessive stomach contents can breach the dam and foods with high sugar contents or similar triggers can stimulate insulin and result in excess fluid production. This effect can lead to a drop in blood sugar and bring on the symptoms highlighted in *Dump-o-meter,* ending with looseness in the bowels. This forms a lovely segue to the next drawing.

44. Bowels (April 2024)
Go into any chemist and you'll see an array of products designed to shut down, speed up or soothe the intestines. To me, this signals all is not well with the human bowel.

I love a good bowel conversation and have never really grown out of certain aspects of toilet humour. I also suffer from 'bowel envy' and would gladly swap places with someone who has a robust, regular system and wait for them to say, 'Ah yes, I get it now.'

I've touched on bowel issues but they deserve a special mention. The above is based on our bathroom and there are times when I've spent more time in there than I'd like. I'm grateful it's not an overly unpleasant room. Dumping syndrome remains part of life but I know my triggers. Things settle down in the longer term so gambling with risky foods becomes a personal choice.

With the exception of 85 – 90% dark chocolate, I eat very few carbohydrates these days. Things to catch me out include overindulging in fresh fruit, with a dollop of cream and this only results in 'green' phase dumping when I simply can get palpitations. If I'm out and about have a limited menu choice, sandwiches and pastries can bring on mild dumping but lining the stomach with vegetables or salad first can prevent blood sugar levels bouncing around. Sticking to the golden rule of not drinking anything immediately after a meal is a pretty safe way to avoid severe dumping, as food is not flushed quickly down into the gut.

Although not in our actual bathroom, the Bristol Stool Scale (BSS) is featured on the wall above. Many people have heard of this but may not be aware of where it came from. It was a team at Bristol Royal Infirmary who first came up with this iconic classification (Reference: Lewis, Heaton [1997]. "Stool form scale as a useful guide to intestinal transit time". Scand. J. Gastroenterol. 32 [9]: 920–924).

The numbers on the loo rolls above are from the BSS but I'd say there should be a 4.5 or 5.5 category for the bowels of post-oesophagectomy patients, which are often on the looser side. That maybe too much information for some so let's move on...

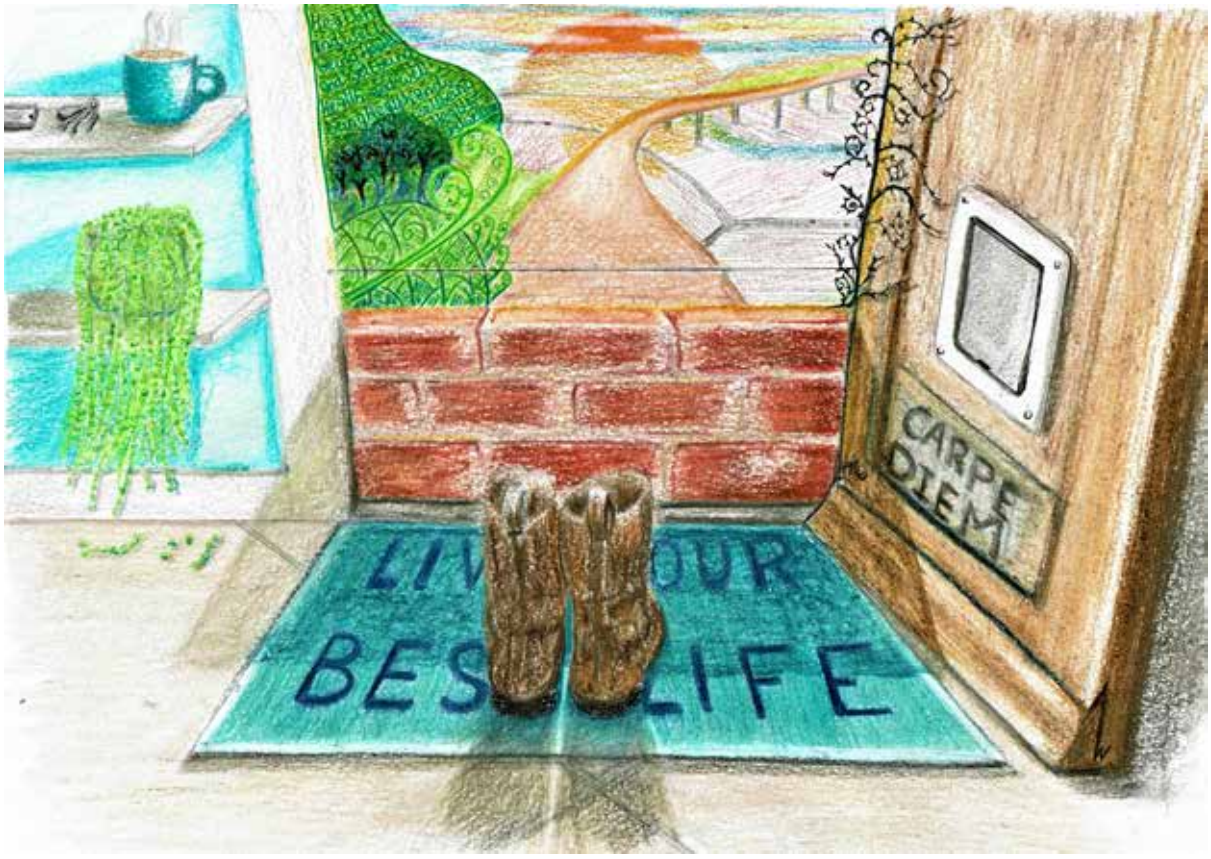
45. Exercise (February 2024)
Exercise comes up time and time again as being fabulous for health and well-being. Regular exercise helps us sleep better, have better digestion, firms up muscles and strengthens bones and joints.

Since surgery, I've really struggled in the pursuit of exercise that does not bring on reflux. Since diagnosis, I've been wary of exercise beyond walking, as the heartburn that led to me being diagnosed came on after several intensive exercise classes.

Returning to exercise after any surgery can be a challenge but for me activities involving lying on the floor are now out, as are ones involving a lot of jumping about.

I tried to go back to yoga and pilates but I felt self-conscious drawing attention to my limitations and could not lie on my stomach or in a position where my stomach was above or level with my head. It all felt too uncomfortable.

I do a lot of walking but as stamina improved, I wanted to do more cardio and weights. I tried quite a few different things but none felt quite right. It took 5 years to find something that didn't interfere with my gut but still gave my heart a boost. I'm thankful for my daughter joining a gym and persuading me to go along. Starting spin classes and lifting hand weights seemed to be the right combination to feel great without squashing my insides and bringing on reflux.

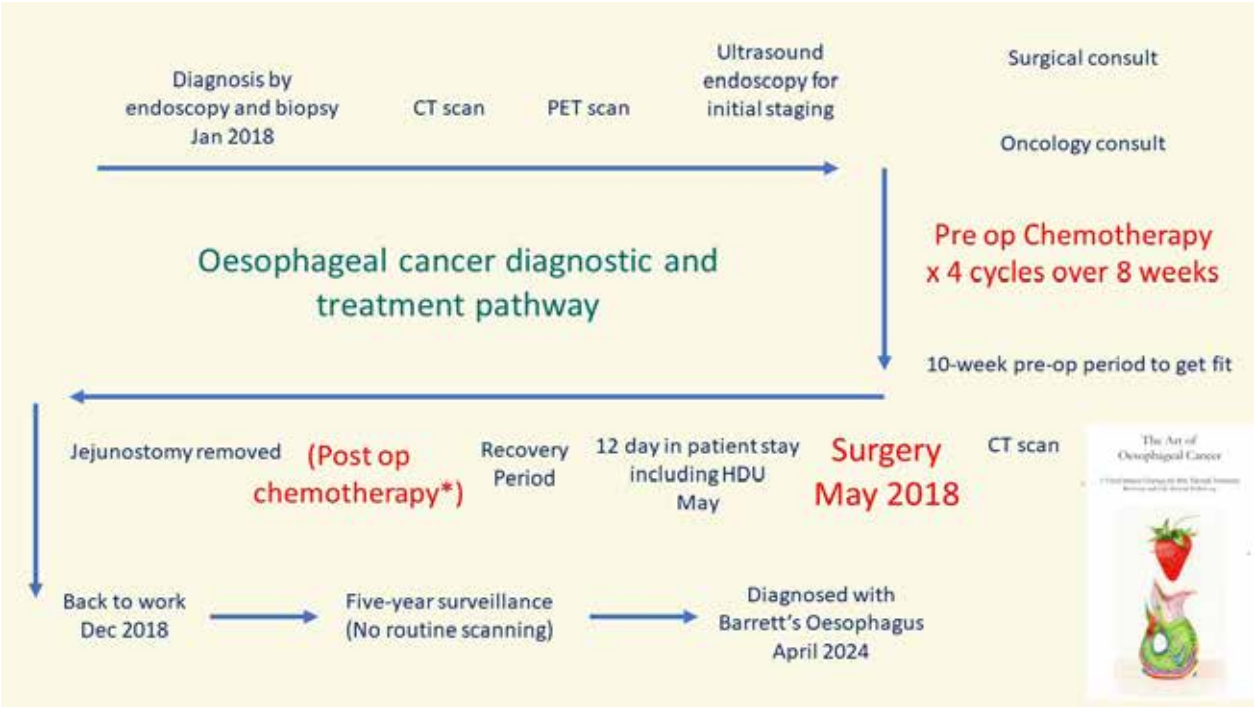


46. On the Threshold of Survival (January 2023)
This image was drawn to mark Less Survivable Cancers Awareness Day on 11 January 2023 and is a symbol of hope after illness.

Survivors of serious illness often have a higher threshold to get over at the start every day. The bricks symbolise physical challenges such as remembering medication, coping with pain, poor quality sleep or energy levels, or ongoing side-effects from treatments.

A trip wire above the bricks represents mental health. Even when you think you're on top of everything, a thought or feeling out of the blue can cause you to fall flat on your face.

At the time of writing, I feel fortunate to be getting through the door most days with few issues. I'm able to live my best life and hope this remains the case for some time to come.



47. Timeline (September 2024)
I was asked to put in a time line of treatment so this is an addition and not found in the printed version.

It shows the steps involved from initial diagnosis to treatment starting and then what follows. As I can easily alter the ebook - I might add more steps and more narrative in here.

*I decided not to have any post-op chemotherapy but this was not an easy decision to make and needed considerable thought and a level of informed judgement around consequences and risk. If I'd had stage 2 and above, I would have certainly gone for the chemotherapy and everything else on offer.

The Barrett's diagnosis is a new thing I'm still coming to terms with it. I'm not sure what it means for someone who has already had oesophageal cancer with no Barrett's but is now seemingly more at risk than before. Leave that one with me...

Closing remarks
Researchers are still a long way off being able to pinpoint who will get oesophageal cancer. Finding out you have it is shocking but if you're lucky to catch it early, quality of life can be good.

The only available weapon for patients is vigilance over symptoms and not relying on long-term use of over-the-counter antacids, without medical supervision. Stopping smoking, limiting alcohol, losing weight and eating a healthy diet, in smaller portions can also help reduce issues with acid, as well as thinking more about the oesophagus and not taking it for granted.

I had no symptoms until a week of severe heartburn came out of the blue, followed by a sore throat and cough but no fever to signal a cold. I had no acid regurgitation either. Looking back, the only significant symptoms were maybe bouts of hiccups and the occasional hollow, hungry feeling in my chest, accompanied by a cold rather than hot sensation – like how the coolness of a mint feels in the throat. Before diagnosis, as well as the heartburn, I had a scratchy, prickly feeling in my chest, especially when I leaned forward.

Below is a list of symptoms associated with oesophageal cancer and the presence of any of these, especially the first one, should signal the need to see a GP:

- swallowing difficulties or a sensation of food sticking in your chest
- pain or discomfort in the chest or back as food passes down the oesophagus
- persistent heartburn/acid reflux/indigestion (persistent would be 2 – 3 weeks without relief)
- regular regurgitation of food
- persistent cough or hoarseness
- persistent hiccups/increased saliva
- persistent nausea or vomiting/poor appetite
- persistent iron-deficient anaemia
- unexpected weight loss/unusual tiredness.

Below are the web addresses of key support agencies in the UK, associated with oesophageal cancer. They work tirelessly running campaigns to raise awareness, supporting patients and carers and advocating for the need for more research to discover better preventative and diagnostic techniques.

- Action Against Heartburn (www.actionagainstheartburn.org.uk)
- Barrett's Wessex (https://sites.google.com/site/barrettsoesophagusuk/home)
- Cancer Research UK (https://www.cancerresearchuk.org/)
- Gastro Oesophageal Support Group Bristol (www.goshbristol.com/)
- Guts UK (www.gutscharity.org.uk)
- Gutsy (www.gutsy-group.org.uk)
- Heartburn Cancer UK (www.heartburncanceruk.org)
- Less Survivable Cancers Taskforce (https://lesssurvivablecancers.org.uk/)
- Macmillan Cancer Support incl patient forum (www.macmillan.org.uk)
- Ochre (www.ochrecharity.org.uk)
- Oesophageal Cancer Fund (www.ocf.ie)
- Oesophageal Patients Association incl patient forum (www.opa.org.uk)
- OG Cancer NI (http://ogcancerni.com)
- OOSO (https://ooso.org.uk)

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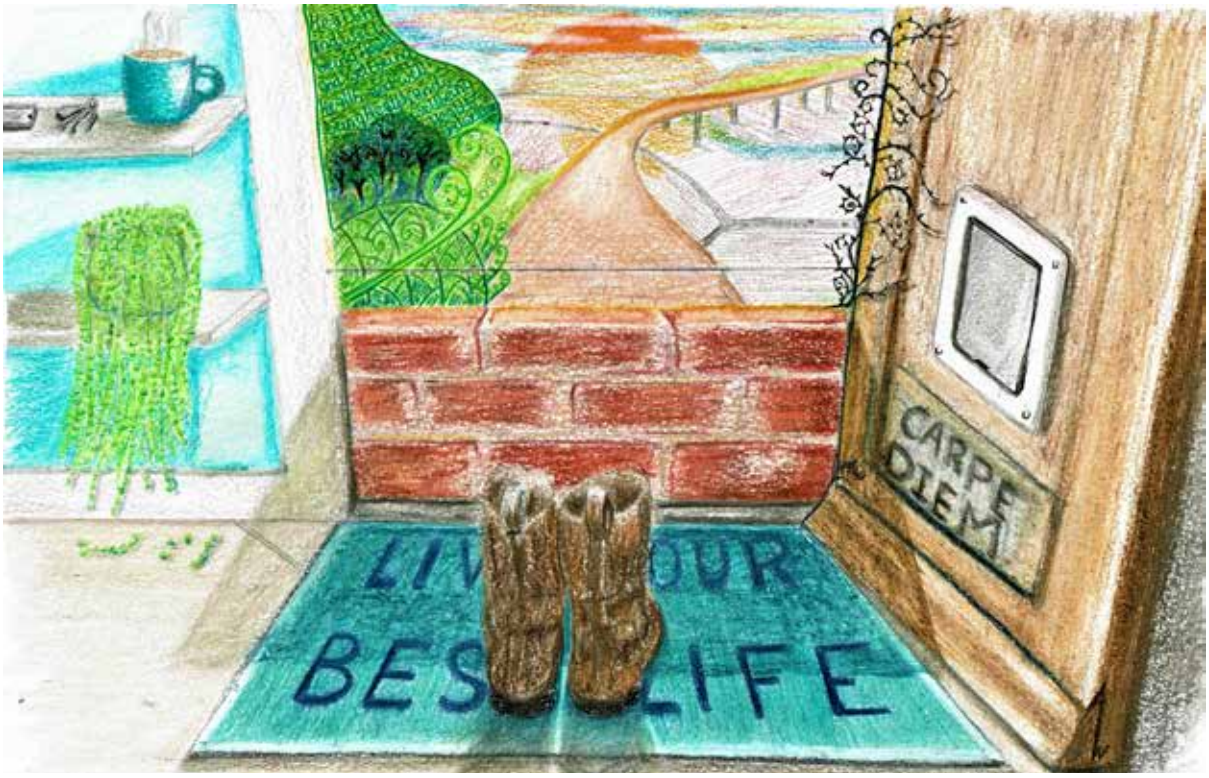
"An incredible insight and I think sums up the journey so well. I'll be sure it has a place on our ward."
(Upper Gastrointestinal Specialist Nurse)

"Your fabulous book will have a huge impact on our service and is much needed. Many thanks for inspiring us."
(Upper Gastrointestinal Surgeon)



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