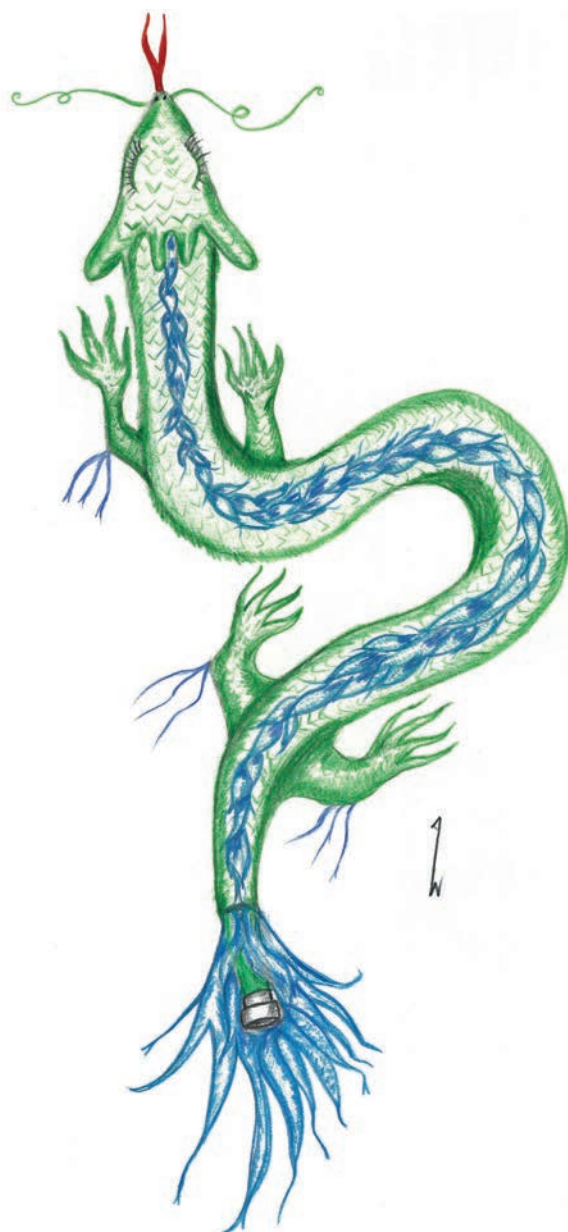


# The Art of Oesophageal Cancer

A visual diary charting the ups and downs of treatment and recovery



Published in the UK by Carotid Body

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A CIP record of this ebook is available from the British Library

First printed in September 2019

ebook version published in March 2021

ISBN 978-1-9993-2402-5

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New editions will be announced on Twitter as @annorthernlass

*This ebook is dedicated to cancer researchers working upstream trying to figure out how to prevent this illness and to Upper GI specialists working tirelessly downstream rescuing people like me from the river*

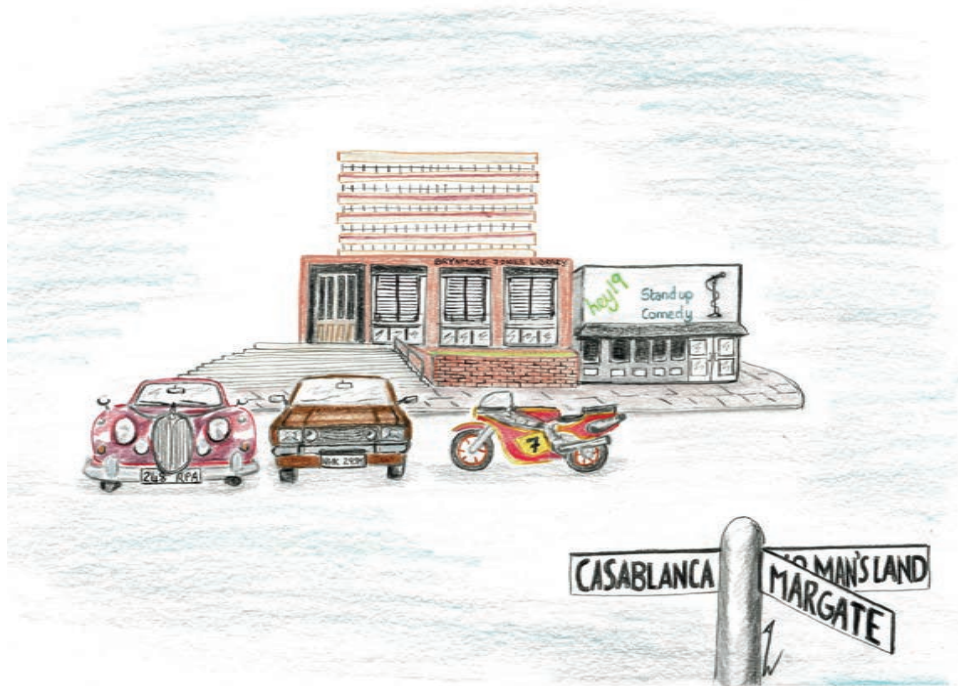
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## Introduction

Cancer of the oesophagus has been responsible for the deaths of many notable individuals including actors Humphrey Bogart and John Thaw, writers Philip Larkin and Harold Pinter, motorcyclist Barry Sheene, musicians Chas Hodges (of Chas and Dave) and Walter Becker of Steely Dan and one of my favourite comedians, Jeremy Hardy. The drawing below *In Remembrance* features symbols of these eight talented men.

## 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 never think much about their oesophagus. It is hidden away and gets on with the job of transporting food and drink from mouth to stomach. Not much can go wrong with it, one would think but it can and if it does, it is a major deal to fix. Like many cancers, oesophageal cancer and indeed stomach cancer, develop silently and are often advanced when symptoms come to light. Oesophageal cancer affects more males than females and is linked to smoking, obesity and acid reflux. It can run in families but as yet no specific gene has been identified.

I was diagnosed with early oesophageal cancer in January 2018 and none of the above risk factors, except family history, applied to me. About 75% of cases are largely preventable by improving diet and losing weight and by not smoking but there are around 25% of patients, like me, for whom the cause remains inconclusive.

The first edition of this book was produced to accompany an art exhibition of the same name that took place in May 2019. Some of the later drawings were done for a virtual exhibition on Twitter (#ocvirtualart) in February 2020 and February 2021 for Oesophageal Cancer Awareness Month. These are my personal attempts to raise awareness of this illness and its treatment.

The original exhibition initially took place exactly a year after surgery to remove the cancer. The operation known as oesophagectomy, involves removal of half of the oesophagus, a third of the stomach and fashioning a new oesophagus out of the remaining stomach and joining it all up again. There is also pre and post-op chemotherapy in the mix.

I have always had a love of art but had only drawn functional diagrams for education in school or university, nothing creative. I started to draw after my second cycle of chemotherapy. It kept my mind busy and helped me get through the side effects and prolonged recovery. I do not expect people to find my drawings pretty and I play around with perspective for effect and for my own entertainment.

I am hoping this book might make people think about their oesophagus and not take it too much for granted. It is important to realise that it is not normal for Gaviscon, Rennie or Nexium to regularly feature in a weekly shop or to have problems swallowing. Anyone in this position should actively seek medical advice and discuss having a gastroscopy (camera to look at the oesophagus and stomach). It should be noted that in the majority of cases, there is nothing wrong but if there is, catching it early secures the best outcome.

This book has been updated during the coronavirus pandemic and I would like to encourage anyone with symptoms mentioned in this book to come forward for investigation.

**Ann Wood, March 2021**



### 1. Upstream and Downstream Health Analogy (January 2020)

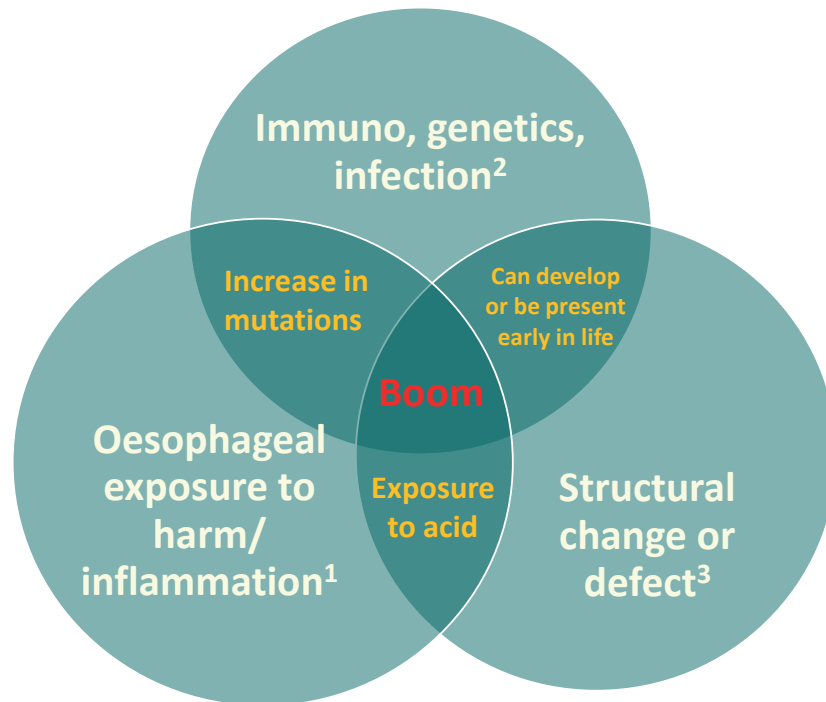
Irwin Kenneth Zola first used the upstream downstream analogy to describe a sickness-based health system. He is essentially saying, instead of rescuing people from the river downstream, why not find and prevent who or whatever is pushing them in upstream.

I wanted to show this visually to highlight the important work done by researchers, epidemiologists and public health specialists, who study the aetiology of disease, how many are ill and who is at risk. Prior to the coronavirus pandemic, these individuals stayed relatively hidden from the front line but use of their data by the media and governments, has thrust these specialties into the limelight.

I use a large carnivore to symbolise disease in general as these formed the main threat to man's early ancestors. In modern times, cancer, heart disease and infection are the new predators. A sabre-toothed tiger represents illness on the more barren, right side while on the left, more lush side, health is restored or improved. Anyone can find themselves on the right side of this valley and as we age, our big cat's territory reduces in size, so ill-health can occur more readily.

Upstream, the people on the right are running 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. Unlike patients with cancer and heart disease, those with covid-19 can and do pull front-line workers into the water but vaccinations should make this less likely.

The pandemic of 2020-2021 has raised the profile of upstream players ie those fighting the big cat of covid-19, especially vaccine researchers, data generators and those identifying people most at risk. There are similar groups of individuals tackling oesophageal cancer and I, like many others, wish them every success in finding ways to prevent this disease.



## 2. The Perfect Storm (January 2020)

The Perfect Storm is a venn diagram I created for the twitter virtual exhibition to show 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 scenarios that may be involved.

### 1 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)

### 2 Immuno-genetics or infection:

Family history, blood group A (link to CA stomach), Y chromosome, stress, bacterial/viral involvement, increasing age

### 3 Structural change/defect/pressure/weakening of lower oesophageal sphincter (LOS) causing gastric leakage

(a) hiatus hernia, achalasia, poor transit through GI 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 overeating or too quickly

c) exercises/activity that could weaken the LOS and aggravate GORD/LPR or a hiatus hernia (eg heavy gardening, inverted yoga poses, ab crunches, waist restriction)

d) LOS relaxing drugs





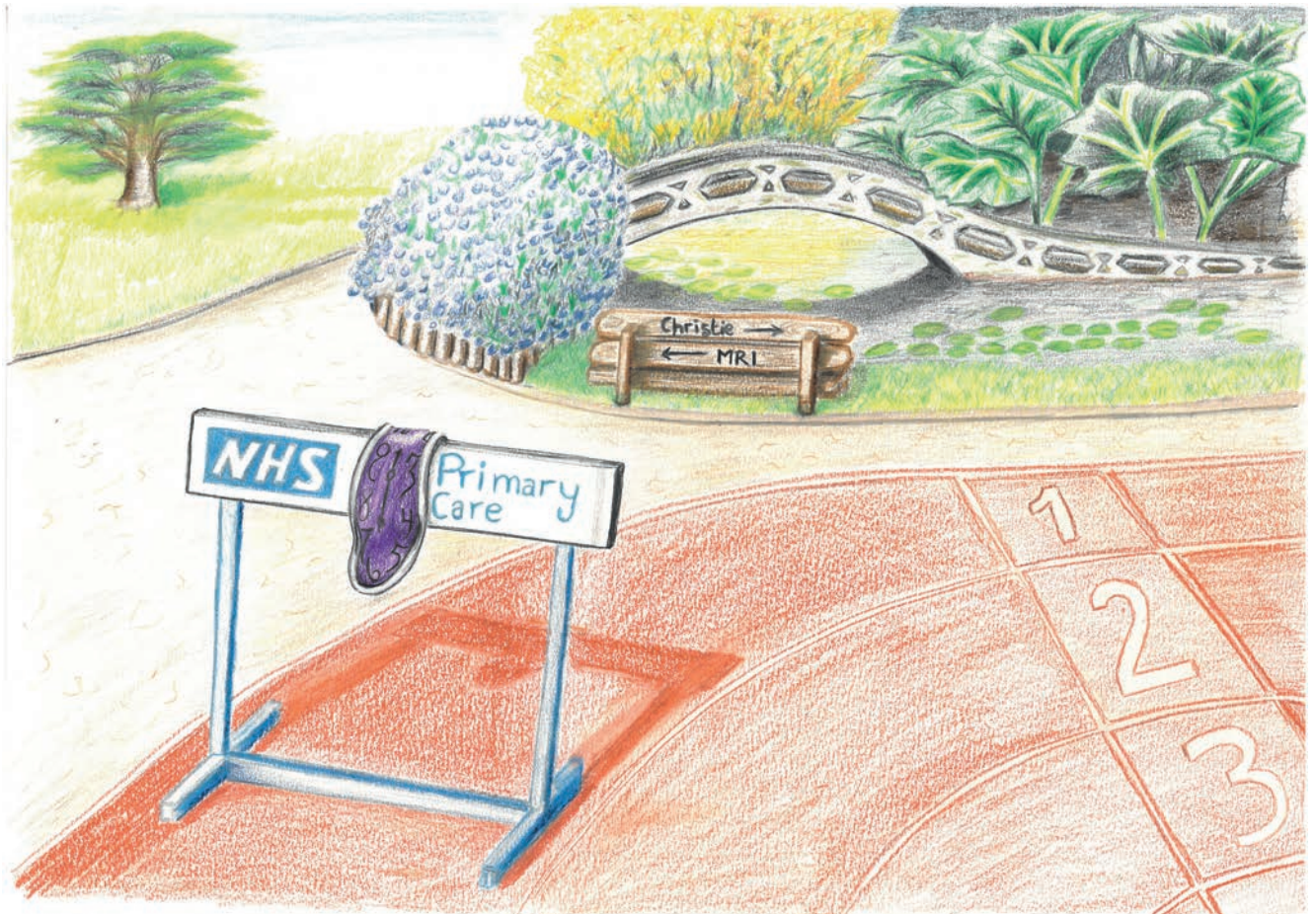
### 3. Barrett's Pinball (May 2020)

This was drawn for World Barrett's Day in 2020 on 16 May. It shows the options around Barrett's Oesophagus as a game of pinball. Some patients experience a back and forward process when presenting heartburn and allied symptoms to their GP (also see *The Race Against Time*).

Although I did not have Barrett's oesophagus, most people diagnosed with oesophageal cancer have this precancer stage so it was appropriate to include this drawing here for completeness.

The traffic light areas right, left and centre (top and bottom) show that ignoring long term acid reflux can increase the risk of oesophageal cancer. By contacting your GP to find out if persistent reflux has caused Barrett's oesophagus to develop, can result in regular surveillance. The right green flipper shows endoscopic radiofrequency ablation (RFA) to remove local occurrences of Barrett's (dysplasia). The left side shows surgery (oesophagectomy) for cancer that develops in a very small percentage of cases. Hopefully early treatment resulting from surveillance allows patients to live longer.

The middle amber section shows that patients on Proton Pump Inhibitors (PPIs) should also have regular contact with their GPs and not be left unsupervised. The red left hand flipper allows some cancer patients to retain the chance to be referred into upper GI services. The right hand amber flipper keeps people in touch with the health system for as long as possible, until mortality occurs through a different condition or old age.



#### 4. The Race Against Time (May 2018)

The above image shows the difficulties that some patients have getting their GP to believe their symptoms are worthy of a referral for further investigation, especially in the absence of red flags. In fact red flags like weightloss and swallowing problems tend to occur once oesophageal cancer is more advanced. In some cases, a patient can be back and forth to their GP several times, leaving more time for any potential tumour to grow and ultimately reducing the range of viable treatment options.

For more early presentations to occur, not only do patients need to present earlier, GPs need to be more receptive and professionally curious over symptoms, especially heartburn and go beyond simply a script for omeprazole. Looking into other factors such as age, family history, lifestyle are also key.

Once diagnosed, there is a well-established and multi-disciplinary pathway in secondary care. This process is portrayed above by a hurdle contrasted against the backdrop of a walk in the park. The park is based on Tatton Park garden which is one of my favourites. They have a beautiful Lebanese Cedar tree and the bridge shown is in the Japanese Garden. Also featured are enormous giant rhubarb *Gunnera manicata* and my particular favourite, the yellow azaleas and blue ceanothus which usually flower around May.

It should be noted that gastroscopy is unpleasant for patients and expensive for the NHS. However more patient-friendly diagnostic tools are being developed to support GPs make better patient selections for further investigation. These include the Cytosponge and a tickbox questionnaire from University College London. GatewayC at Christie Hospital has also developed an online education package for GPs, based on patient consultations. The aim is to help GPs be more confident in selecting and referring patients for cancer investigation.

These are all good innovations but they will only work if significant numbers of patients' age, gender or relevant presenting symptoms tick the right boxes. If not they have an even higher hurdle to get over to convince their GP to refer them on.



### 5. 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 floating poison bottle shows chemotherapy as both a strong deterrent and a cause of lingering side-effects.



**6. The Chamber of Closed Doors (April 2018)**

In *The Chamber of 32 Doors* from the album *The Lamb Lies Down on Broadway* by Genesis, the character in the song is stuck in a chamber where every door he goes through brings him back to the same place. This is how I saw myself during my treatment and living with cancer itself – there is no escape, especially with the ever-present risk of recurrence. I also felt more personal doors were closed and some may or may not reopen. The drawing depicts a sinister discomfort and frustration but the level of both emotions reduces over time.



**7. If You're Going Through Hell (May 2019)**

I had chemo at Christie Hospital in Manchester and despite the huge efforts made there, to make the patient experience look and feel pleasant, my pet name for it was Hell, as they do horrible things to you there. However, it is all done with the best of intentions and at every visit I encountered genuinely lovely staff and patients. The brother of an American Medical Oncologist undergoing treatment summed up perfectly by describing his cancer treatment centre as:-

**“an elegant torture chamber staffed by the kindest humans in the world”.**

(J William Eley, Medical Oncologist Emory University, Atlanta, GA).



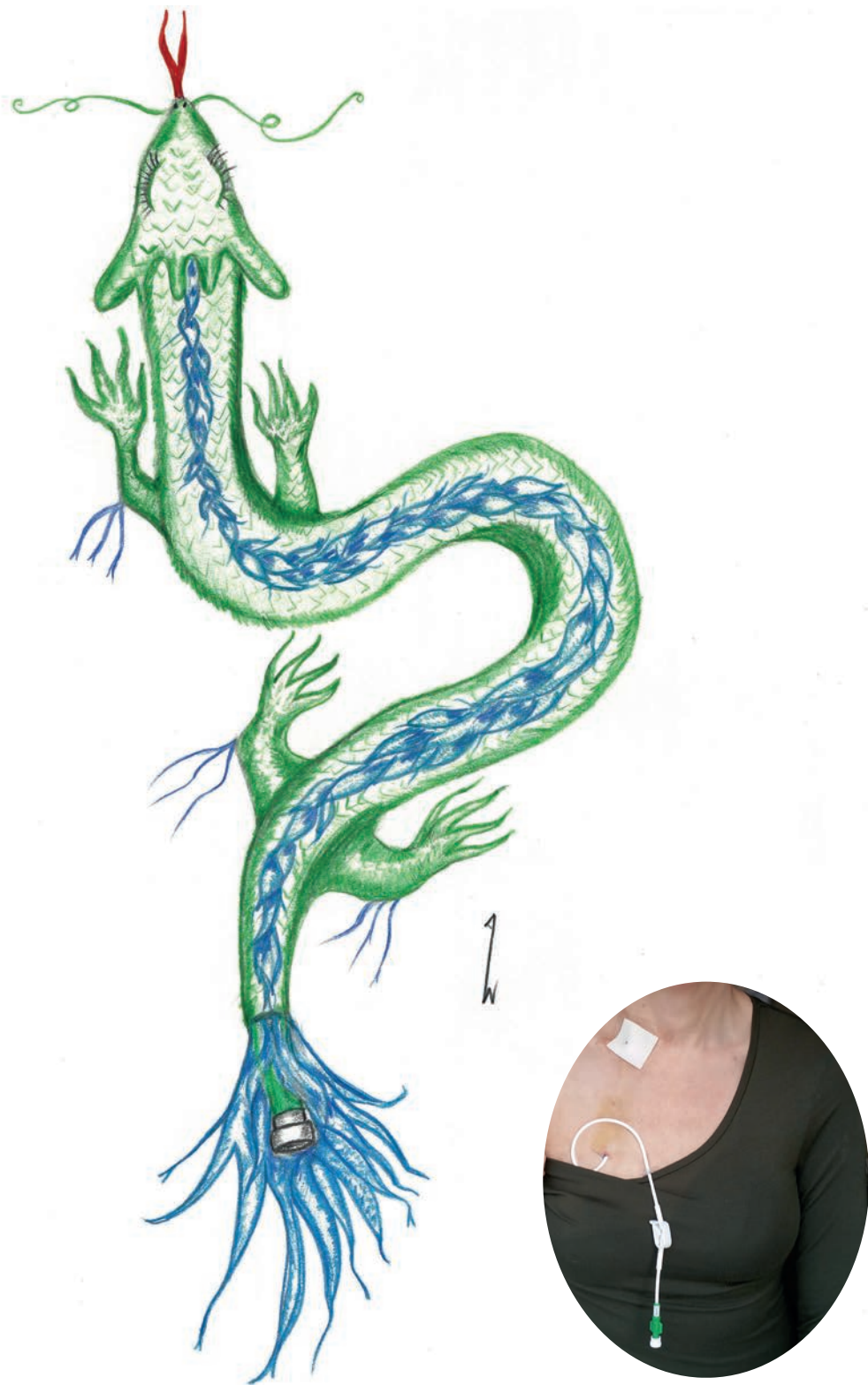
### 8. Tethered (December 2019)

Tethered is an updated and more reflective version of *If You're Going Through Hell*.

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

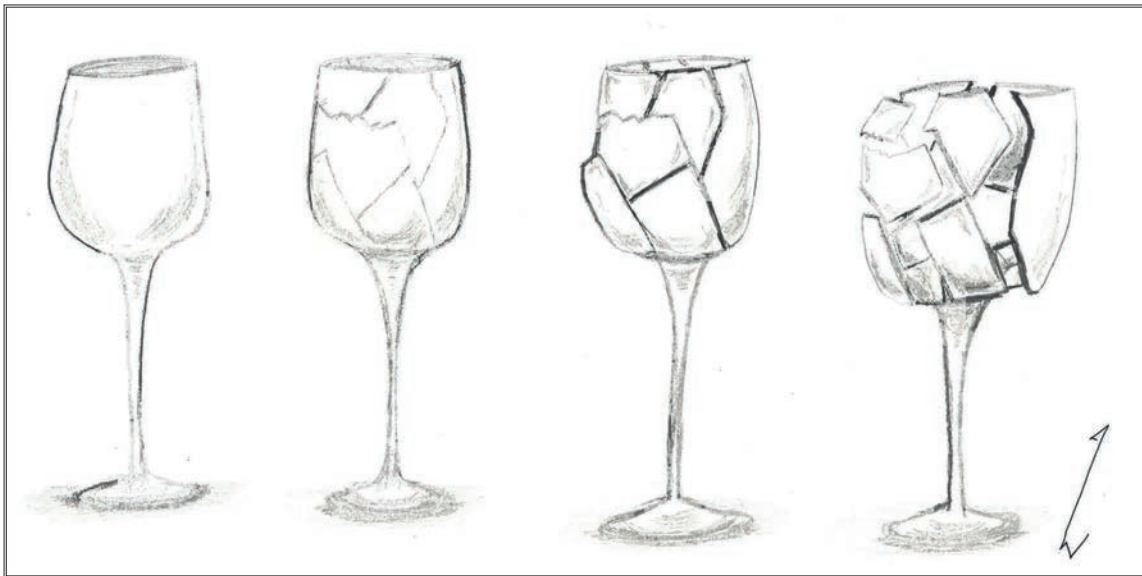
As a cancer patient, even when you are not undergoing treatment, you have to monitor temperatures and return to your cancer centre between treatments for blood tests and check-ups. In addition, when out and about you need to safeguard yourself from infection by keeping up good hygiene, regular handwashing, limiting contact with others and avoiding certain foods. Months, even years, after chemotherapy has finished, one can remain tethered to the memory which, although fading into the past, still remains a huge part of life. The learned hygiene measures have been helpful in the current pandemic.

The numbers on the right of the volcano represent the 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.



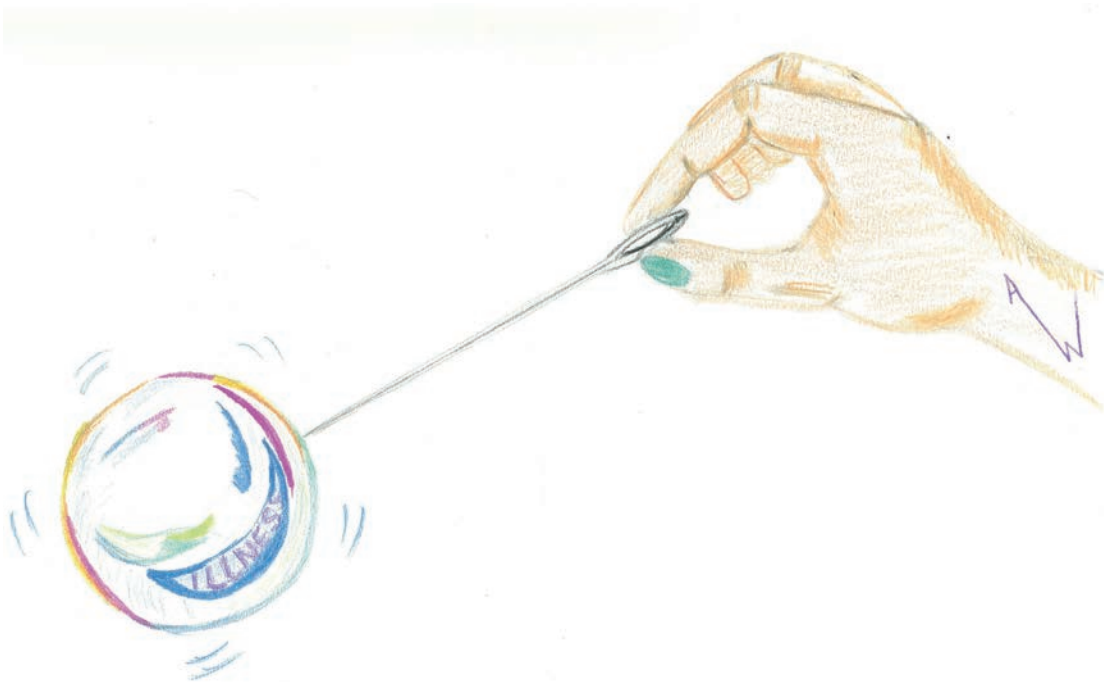
**9. The Hickman Dragon (May 2018)**

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. It stays in place until treatment is complete so facilitating the process of getting long infusions of drugs in and regular blood samples out. The tube is always looped to prevent it 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.



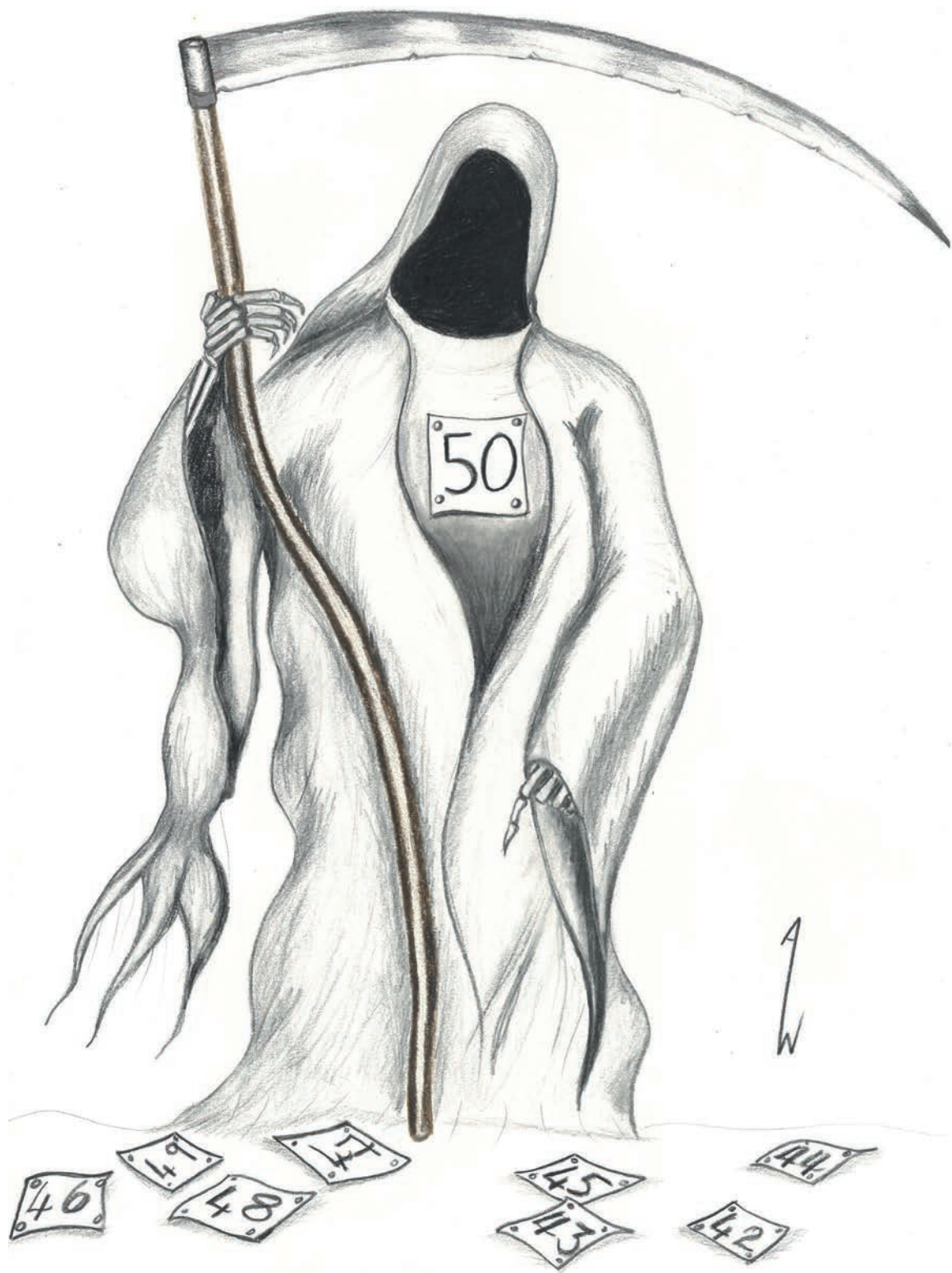
### 10. Hair Loss (April 2018)

I had a lot of long, thick hair before chemo and like others in the same position, I had it cut short before treatment began. My hair started to shed significantly after the second cycle. It started slowly and then my hair became too unstable to touch or even wash so I wanted to show this fragility. I felt the resonant sound frequency of glass was the perfect analogy to the concentration of drug that makes the follicles shut down and the hair fall out.



### 11. Bursting the Bubble of Illness (May 2018)

The end of chemotherapy brought about a period of rest and recovery ahead of surgery. This I called a reprieve from being in the bubble of illness. I felt good at this point and started to exercise again to build up my strength. Going back to work until the operation also made life feel more normal and helped the time to pass.

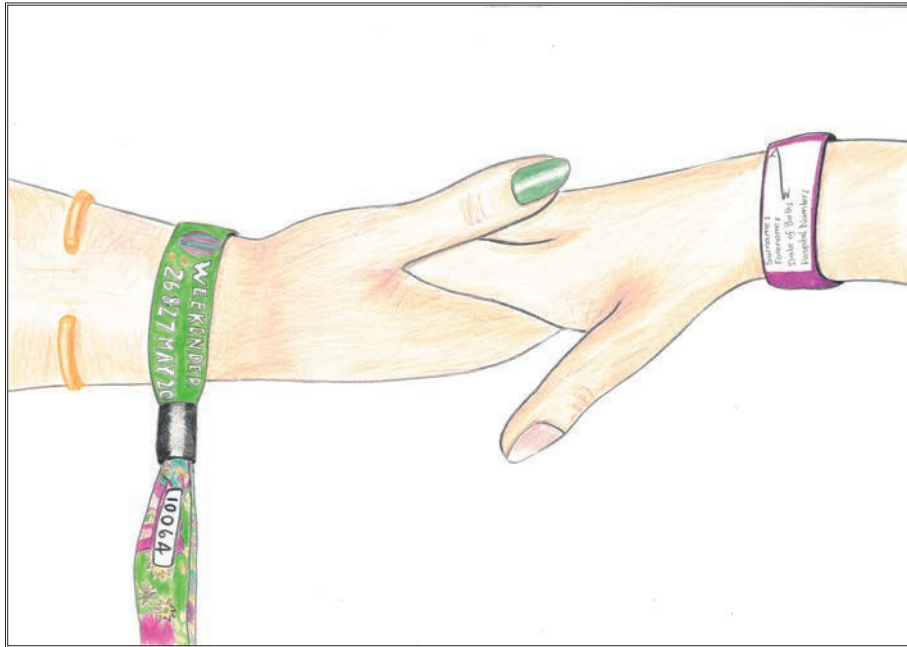


### 12. The Run up to 51 (May 2018)

As I grew older, I became more acutely aware that a number of close family members had died in their 50s. This drawing is all about my apprehension around reaching this decade.

My surgery was to take place a few days before my 51st birthday and I was genuinely worried that I may not see it. All surgery carries risk and I had been told that 10% of oesophagectomy patients do not make it out of the hospital. I drew this 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 now one of my favourites.





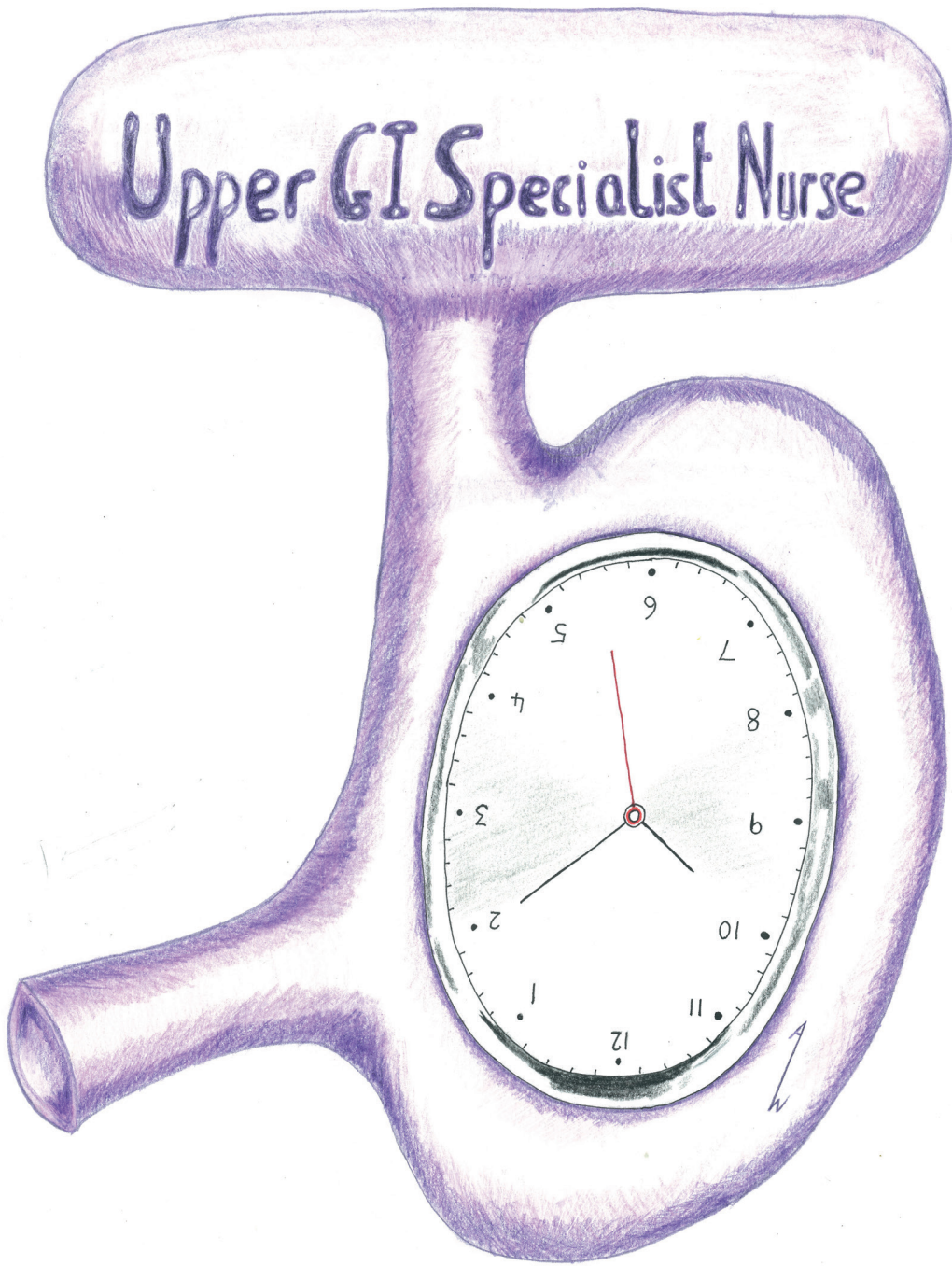
### 13. Wristbands (June 2018)

Before the covid pandemic, I was a regular concert goer and two days before surgery, I attended the very first Warrington Weekender music festival. I'd bought the tickets long before I was diagnosed and was really looking forward to going. The drawing above shows the festival wristband being swapped for a hospital one. The hands represent a reassuring handover from my network of support and free-living self to my institutionalised self. A year later I attended the Warrington Weekender again on 25-26 May 2019 and wore a hospital wristband the week before for a check endoscopy, which thankfully came back clear. The 2020 Weekender has had to be rescheduled to September 2021 because of the covid-19 restrictions.



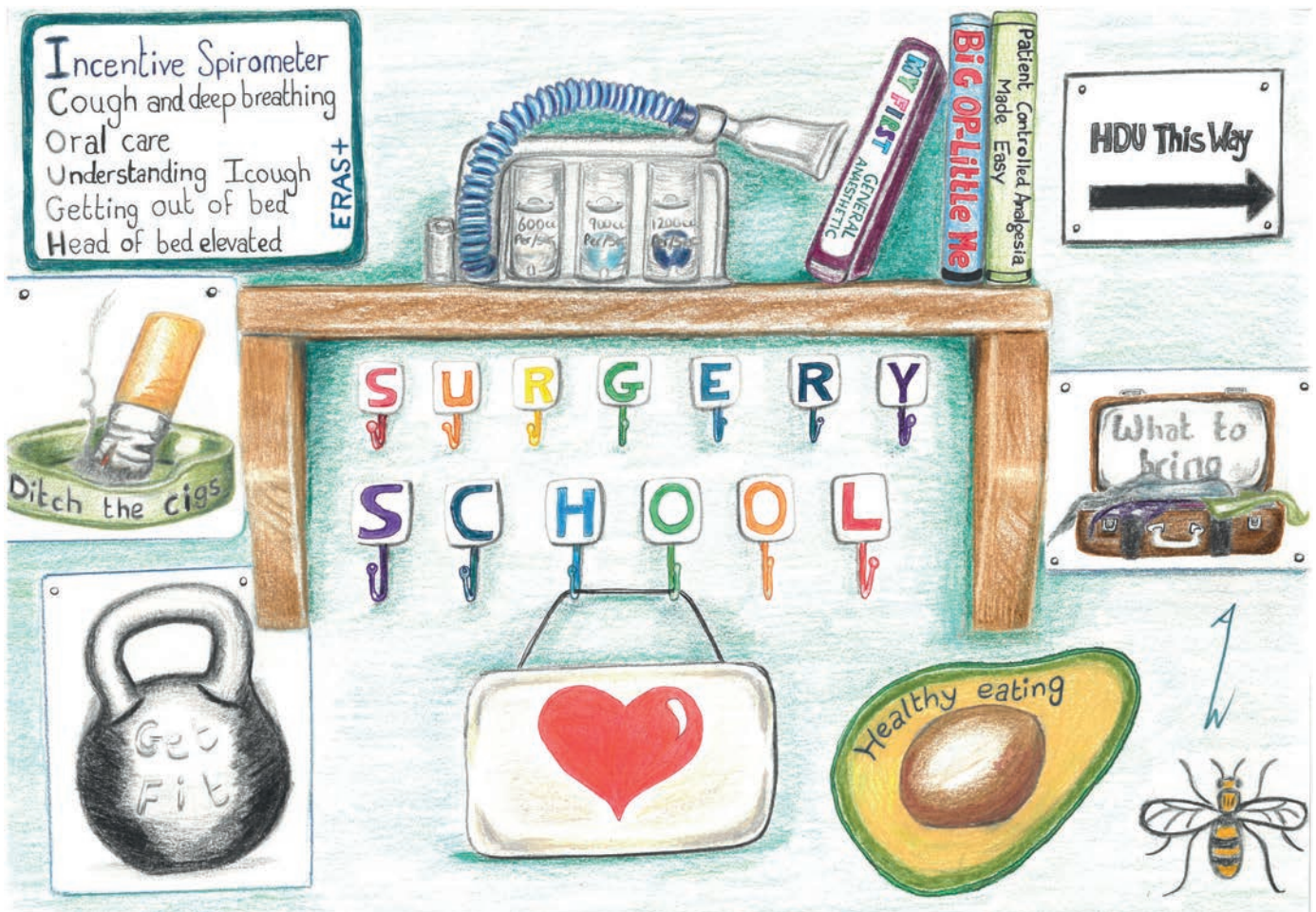
### 14. Accrington NORI (May 2018)

The Accrington NORI is an iron-hard engineering brick, made in Lancashire. It was used in the foundations of buildings such as the Empire State Building and Blackpool Tower. It is a thing of great elegance and strength, with its essential core values coming from Accrington. I am grateful for my own core values and strength, which were passed down to me through my Lancastrian-born ancestors. The NORI is of enormous sentimental value to me and for this reason this picture is dedicated to my daughter, who was a brick during my illness.



**15. Fob Watch (September 2018)**

This variation on a nurse's fob watch resembling a stomach, pays homage to the Macmillan Upper Gastro-Intestinal Specialist Nurses who supported me throughout my treatment and still do. They are wonderful and only a phone call or email away if you need them.



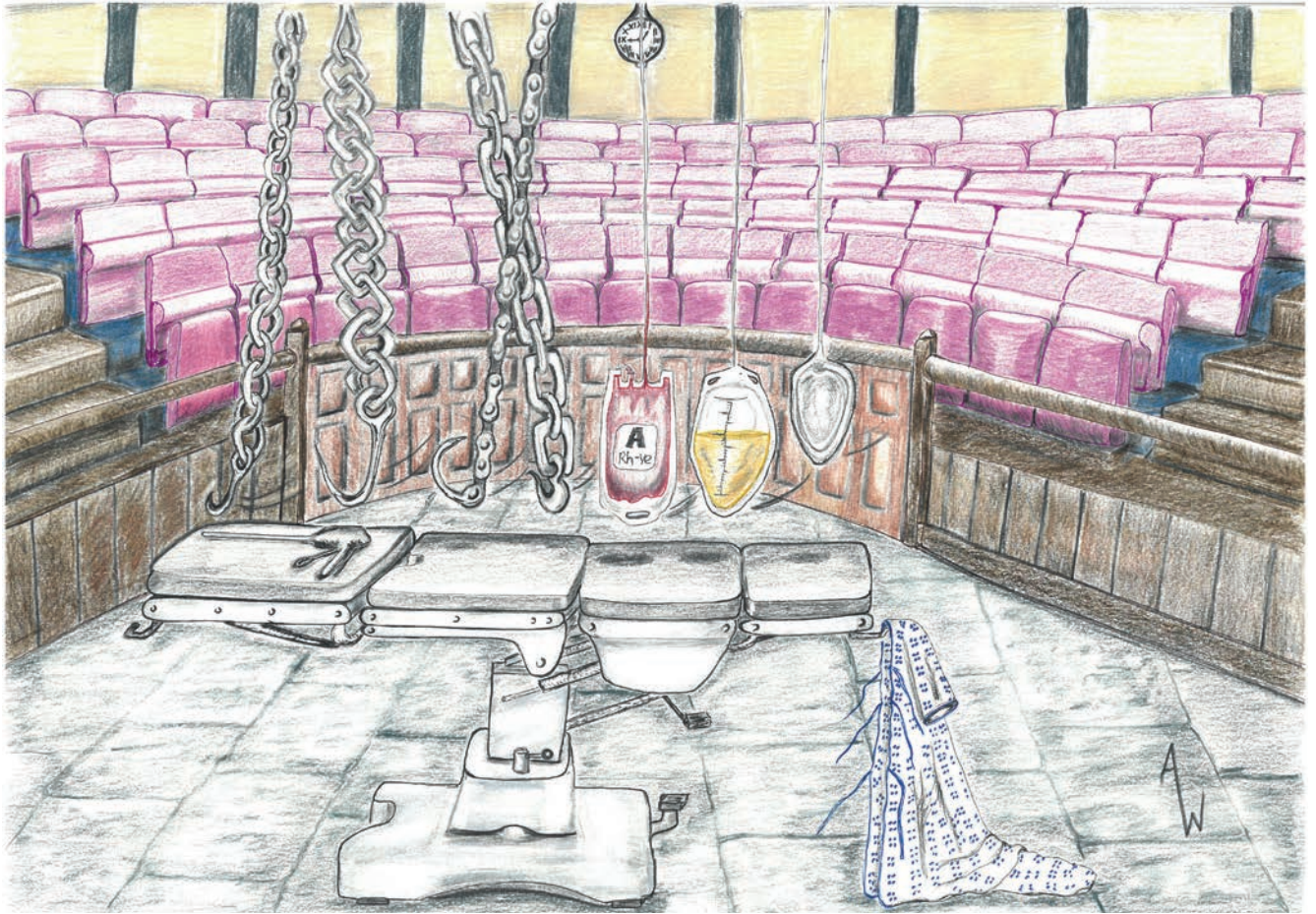
### 16. Surgery School (November 2019)

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.

The meetings include advice on diet and exercise, a visit to the High Dependency Unit and the receipt of an incentive spirometer (below) for use four times a day before surgery. This is 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 Centre in the USA. Chest infections post-surgery are a common complication and ICOUGH aims to reduce the incidence.

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





### 17. Hell-raising Surgery (October 2019)

The image captures the loneliness and vulnerability felt by a surgical patient in a piece of sewed cotton, surrounded by lots of people.

Being told my op would be keyhole and I'd have a number of cuts, made me think of the horror film Hellraiser. The film features a room with hanging hooks that rip victims apart.

The scene is before the start of the operation and has a backdrop of an anatomy theatre, with equipment and hospital gown. The seating is based on the Royal Institution in London, which in April 2019, hosted Cancer Research UK's 3rd International Symposium on Oesophageal Cancer. I was very fortunate to be able to attend this event as a patient rep.

I also wanted to show here that there are not enough seats visible for all the NHS professionals who had a role in my care ie, endoscopists, nurses, radiographers, dietitians, physiotherapists and oncology, surgical teams, receptionists and catering staff.

Surgery is like legalised assault. Your surgeon tells you they'll inflict GBH on you and you might die. You sign a form to say that is OK and one or two people do the wounding while an entire team of individuals ensure that you do not feel a thing. Another team gets you well and continues to check up on progress and see that you are OK several months/years later.



### 18. Incarceration (November 2019)

This is about the effects of loss of liberty while on the High Dependency Unit (HDU). As a first surgical inpatient and HDU stay, I did not appreciate how hard it would be being holed up for several days. I also expected to be in a drug-induced stupor and did not expect to feel so mentally sharp, which made being locked in all the more difficult.

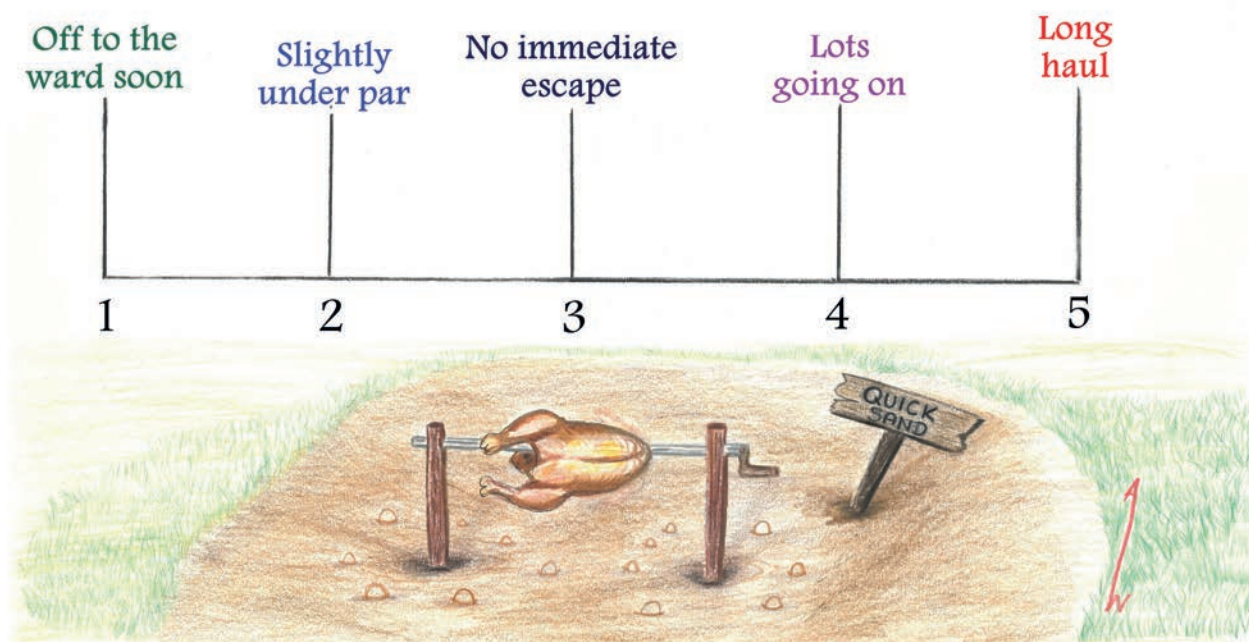
Manchester City Centre is in the background but the inspiration for the main HDU block came after a city break to Belfast in October 2019 and visit to Crumlin Road Gaol - an incredibly interesting, visually elegant, albeit macabre, place to visit.

The cactus garden on the far left symbolises the feeling of 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 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 a number of essential consumables being used like vomit bowls, lengths of tubing, huge drain buckets and daily changes to bedding and gowns. This gave me the idea for the underground storage rooms to add some depth to the picture.

Once on the ward and more mobile, I sought out somewhere to walk to and sit to enjoy the unusual heatwave Manchester was having in June 2018. Hospital surroundings can not be made too pleasant but what green spaces they had were for decoration not function, hence the keyhole entry to the right. I felt like Alice in Wonderland with no key to the garden. Consequently, I spent time pacing hot corridors looking like a wraith and alarming people who were passing by.

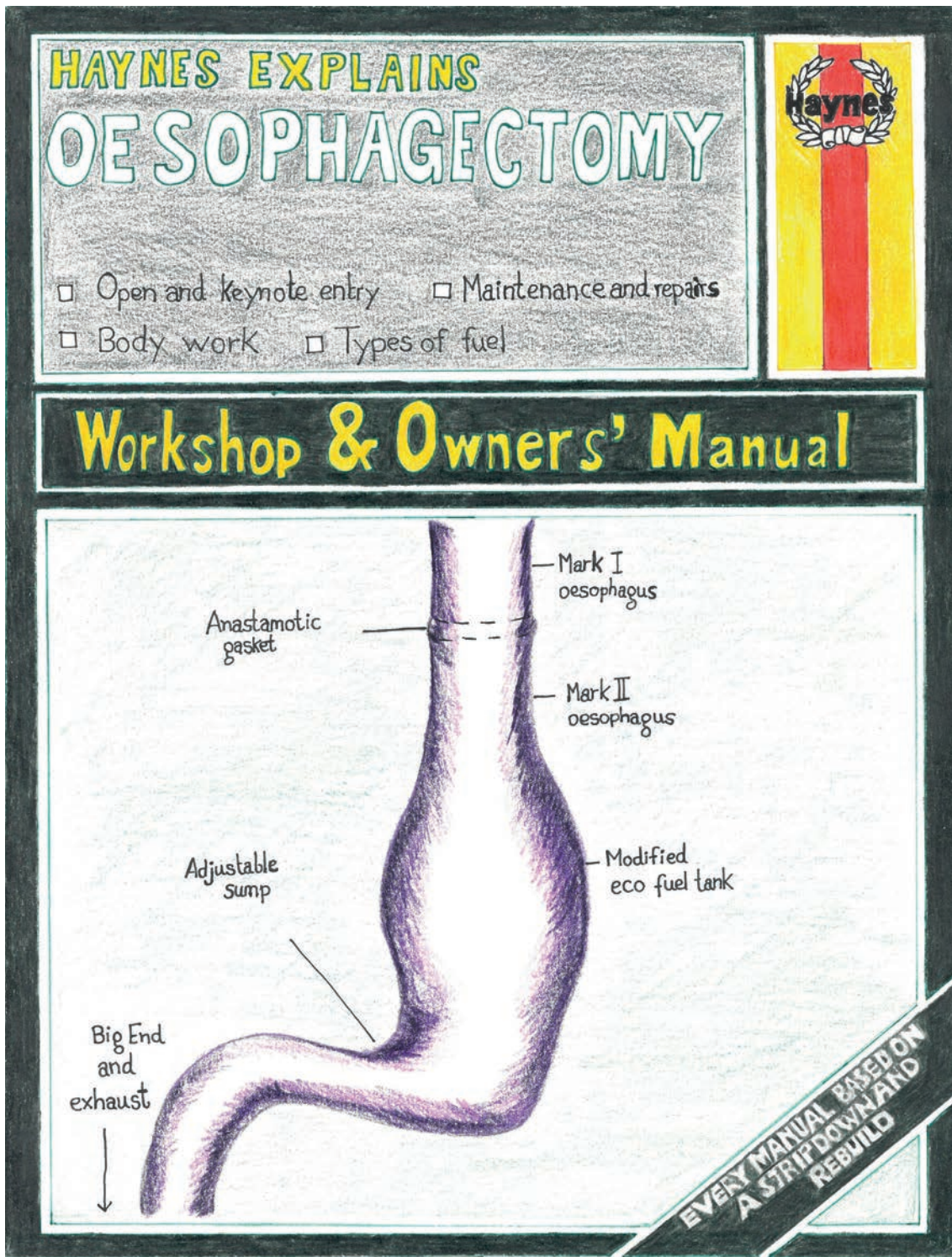
# THE SCALE OF SUFFERING



## 19. The Scale of Suffering (July 2018)

It was quite humbling being on HDU as we were all suffering in one way or another. Not due to lack of care, simply suffering from being physically unwell. I was somewhere in the middle of the scale but my heart went out to those higher up. I remember all my neighbouring patients, particularly someone brought in after a road traffic accident and miles from home. I felt so sorry for this person as they probably had started their day thinking they would be home in time for dinner. Instead they ended up in an unfamiliar hospital, unaware of how they got there and suddenly having to be helped in and out of bed to use a commode. I was thankful I knew where I was and how I got there and prior to surgery, had the liberty of walking down to the operating theatre.

The HDU beds themselves were also an experience. The mattresses were as soft as quicksand, making it impossible to get any purchase to move, let alone escape. My mobility was hindered not just by all the tubing but the epidural had to block nerves to the core abdominal muscles and this felt like a corset of wood. I was surprised at the extent to which core muscles were needed for pretty much every movement. The mattresses were "anti-pressure sore" and inflated and deflated automatically so nursing staff did not need to lift and shift anyone. These ongoing cycles rocked you ever so slowly back and forth like a rotisserie chicken.



### 20. Haynes Explains Oesophagectomy (August 2018)

Anyone who has attempted to service their own car may have used a Haynes manual. I wished that there had been a similar manual to tell me what to eat, in what quantity and how to trouble-shoot problem symptoms. Instead each food and portion size had to be tentatively tried and tested until it yielded the most comfortable results.

**Surgical Top Trumps**

### Minimally Invasive Oesophagectomy

**BEFORE**                      **AFTER**

Performed to remove tumours at the oesophageal-gastric junction. Minimally invasive refers to the keyhole/laparoscopic nature of the procedure. Despite this less extensive approach, the duration of surgery and recovery time are still significant.

Duration of surgery	8 hours
Surgical complexity/skill	9
Medical intervention	9
Length of inpatient stay	11 days
Degree of scarring	5
Post-op recovery	6-18 months

#### 21. Surgical Top Trumps

Not many people seem to know what an oesophagectomy involves, so I drew this to help inform family and friends. It has helped people appreciate why eating normal-sized portions is now no longer possible.

“Minimally invasive” refers to the procedure being “keyhole” rather than a larger open incision. Instead there are several small cuts rather than one large “shark bite” wound. However, the small scars on the outside do not reflect all the work done within.

Treatment for oesophageal cancer is extremely complex and this drawing only hints at its scale and sophistication.





### 22. Normality (August 2018)

Above refers to how I felt at around nine weeks post-op and the longing for normality. I am the train wreck (or as a good friend preferred to describe me, a derailment) and the road to the left is my recovery. I felt I was two thirds of the way up but still had a few obstacles to negotiate. One was a ruined tower representing the psychological side of cancer. You can often get stuck in there, 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 is a book by Stephen King [and a film] about a group of prisoners on death row in the 1930s).



### 23. Milestones (December 2018)

The reverse mincer represents the physical side of post-op recovery, in terms of wound healing and getting back to normal activity. After such a massive operation, you do feel you have been through the mill a bit. I had five incisions, three chest drains, one feeding tube and a broken rib to contend with. The eight milestones above show progress up a mythical beanstalk. I use a beanstalk in a number of drawings to symbolise health, growth and strength. In reality, recovery and learning how to adapt extended beyond returning to work at 6 months but for this drawing, it seemed an appropriate place to stop.



#### 24. Weight Loss (August 2018)

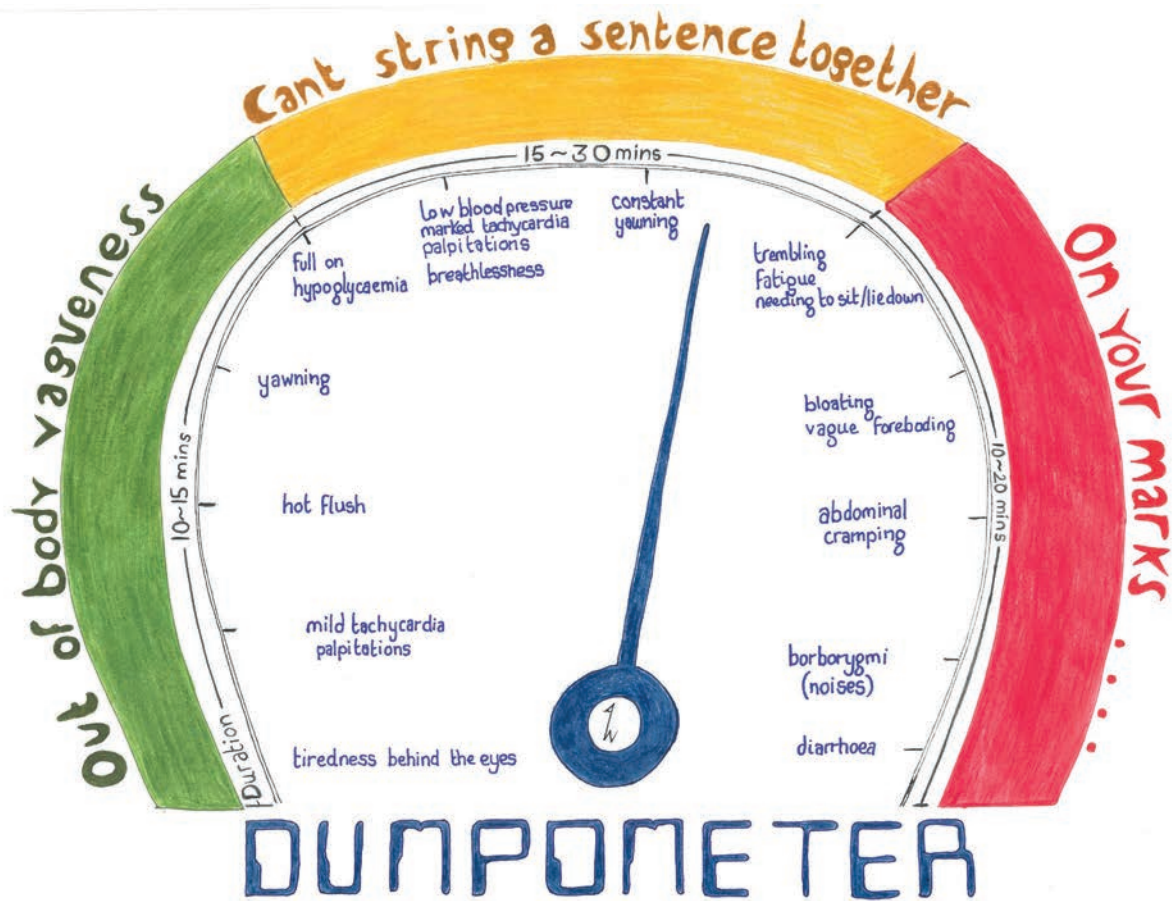
Oesophagectomy is similar to bariatric surgery in that it reduces stomach capacity. With only a third of the stomach remaining, eating smaller portions by the clock is the way forward and significant weightloss can occur (10% of bodyweight is normal). Weight loss can be minimised by use of a jejunostomy feeding tube (jej or j-tube) and this helped me enormously. I found that after four months, the tube was no longer needed so it was removed.

I have always been slim and would describe my appetite as good but not huge. I deliberately put on a few pounds before surgery and to maintain weight afterwards, I took on board advice about fortifying food and kept a food diary of calorie and nutritional intake. My weight stabilised at around four months post-op and at 12 months, I felt much more confident about the type and quantity of food I was able to eat.



#### 25. A New Way of Eating (November 2018)

Learning what and how much food you can eat after oesophagectomy is not an exact science and changes over time. Everyone is different. Little and often, no drinks with meals, methodical chewing and easy on sugar were my keys to success. My meal sizes are now 60% of what I used to be able to manage. The amount of food I can now eat is sufficient to meet both my nutritional and energy needs with the added bonus that eating small meals is a good way to prevent heartburn.



## 26. Dump-o-meter (December 2019)

This describes my experiences of Dumping Syndrome (DS). This is a common post-op side effect of any gastrointestinal surgery, particularly oesophagectomy. There are both early and late forms of DS but my experience was triphasic and occurred soon after eating.

I'm not including the science, suffice it to say, DS is a form of reactive hypoglycaemia and incredibly unpleasant, even in its mildest form. Some people counteract the effect by eating more sugar, whereas I prefer to ride it out as I find more sugar compounds the issue (ie it makes you crave sweet foods all the more).

The green phase occurs the most frequently and most of the time does not go beyond that stage. I can function in green, it's mainly a slightly raised heart rate and feeling slightly zoned out. Progression from green to amber renders you unable to string a sentence together for 15 mins. Amber is characterised by tremors and my resting heart of 60 odd would sometimes double, which felt grim.

Amber progressed to red relatively easily in the weeks immediately after surgery and made life unpredictable. This improved massively around 3 months onwards and although it can still happen, it is extremely rare now.

Triggers for DS include eating/drinking too much/too quickly particularly following a longer than usual interval between meals. For the first year, breakfast used to send me frequently into amber and if driving anywhere, especially to work, I had to wait for it to pass off. Sugar/starchy carbs can also be triggers. Eating fruit and veg, even as a smoothie has never been a problem for me but can be for others. Everyone is different.

My golden rule for avoiding problematic DS is to never drink straight after a meal, especially a small one and generally always drink fluids slowly and carefully, regardless of whether any food has been eaten. Even water can cause issues if it pushes stomach contents too quickly into the small intestine.





### 28. For the Love of Alginate (December 2019)

The image above is about discovering something is an integral part of your life when previously, you had never given it a second thought. This was the case for me with alginate, a natural gel-like substance extracted from kelp, which has many remarkable uses. It is a key component of modern over-the-counter antacids such as Gaviscon. On contact with gastric secretions, it forms a protective barrier between the acidic contents of the stomach and the oesophagus. As the valve to close off the top of my stomach has been removed, I am prone to acid reflux so I now always carry a supply of Gaviscon.

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 have gone from knowing nothing of alginate to fondly regarding it as a natural treasure.



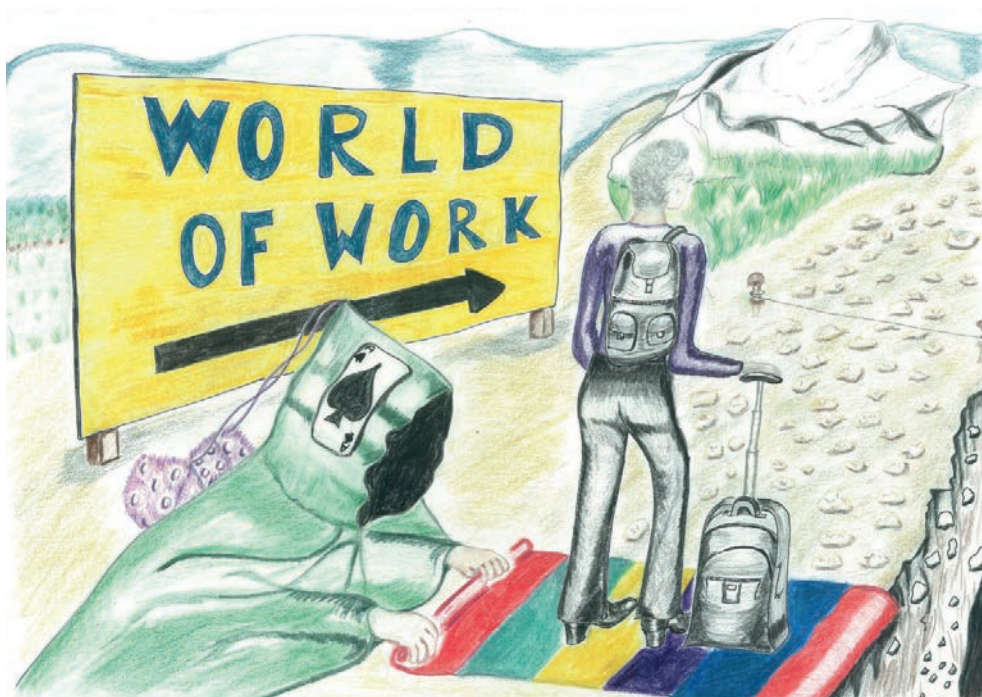
### 29. A New Way of Sleeping (November 2018)

Oesophagectomy can cause reflux to occur when lying down, therefore patients are advised to sleep more upright. To achieve this, I use a mix of different types of strategically-placed pillows including a wedge. Some people find putting the bed at an angle helpful, while others find an automatically, adjustable bed works best for them.

The benefit of using pillows alone is when away from home, you only need to ask for additional pillows and if you get funny looks, you can say it is due to acid reflux.

I miss being able to lie flat though and can only sleep comfortably on one side. I used to love having a cheeky nap, doing yoga and having a massage but these are more problematic now.

Another preventative measure is to not eat too close to bedtime but I find an empty stomach causes more problems. Everyone is different. Although coming to terms with post-oesophagectomy lifestyle changes is tricky, it is far better than the alternative.



### 30. World of Work (December 2018)

It is a big deal going back to work after a long period of sickness, especially when cancer was the reason behind the absence. I was determined to try to go back after 6 months but was not sure whether Fate might pull the rug and my plans would have to be changed.

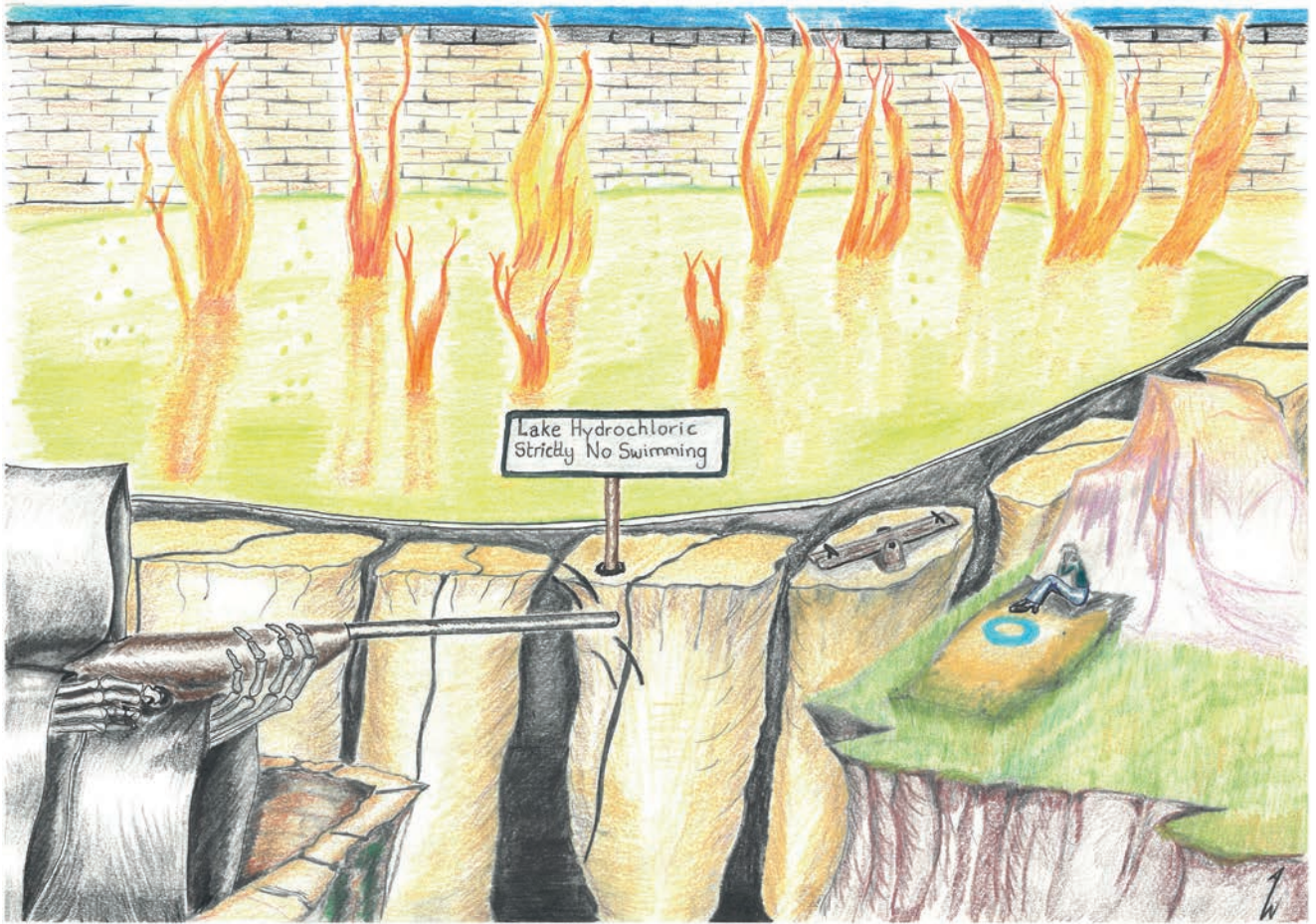


### 31. Princess and the Spices (November 2020)

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 am able to detect even the smallest quantities of some spices in foods as they sting my oesophagus on contact. The main one being chilli and I liken this to when you chop up a chilli and accidentally rub your eye. The effect of capsaicin (active ingredient in chillis) in contact with your eye is something you know about! A similar thing happens with pepper, ginger, mint and citrus fruits. I assume this effect is due to some residual sensitivity or nerve damage in the oesophagus, so for now I tend to avoid these foods.

The huge pile of mattresses shows the unconventional sleeping arrangements you may have to adopt as mentioned in *A New Way of Sleeping*.



### 32. The Wobble (March 2019)

The Wobble is about mental health and encapsulates the loss of confidence I had with my life and my body and still have to a certain extent. It is definitely the darker side of cancer as after diagnosis, you can easily find yourself taken hostage by every new symptom, however minor. Surgery leaves you with several scars, nerve damage and a reconfigured digestive system, resulting in a plethora of new sensations. An ongoing challenge is acid reflux and as said earlier, I now take medication every day and the occasional Gaviscon, to keep it at bay.

I define a wobble as a period of time where worry is all consuming. Although transient, it is still unpleasant and so far I have been able to shake off the feeling by concentrating on the present. Wobbles can occur when unexplained symptoms arise and the 'what if' conversations start doing the rounds in your head. I got my first major wobble after a bad flare up of acid about 9 months after surgery and had another 18 months later.

The image above shows a sniper popping up and taking aim regularly at either me or the see-saw, which is present to symbolise the switch from normal cells into cancer. During a wobble, the future is shown as blue sky but it is obscured by a brick wall. I am trapped on a precipice between a rock and a hard place. It is a grim image but it has helped me to come to terms with living under threat.

It is sometimes hard to shake off a wobble and seeking support may be necessary. As time goes on, wobbles do get fewer and more far between but uncertainty is always there. As a friend and former cancer patient said

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





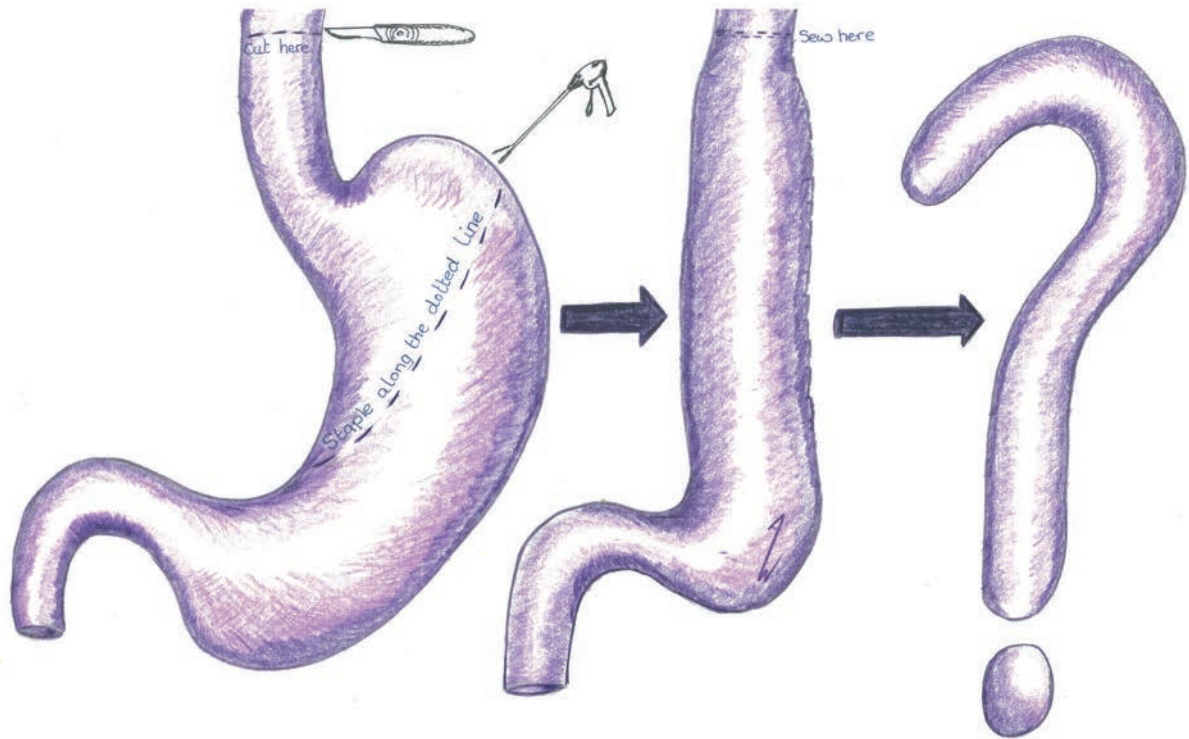
### 33. Pickaxe Headache (December 2020)

This image depicts how the management of a pre-existing condition has to be factored in to the post-surgery lifestyle. In my case this is migraine and I appreciate that other people have long-term conditions that are far worse.

Although these headaches have improved significantly, you can end up concentrating on ensuring you have eaten enough that you forget to drink enough fluids. I am someone who needs a lot of water and this can be a challenge especially on hot days or in hot environments.

If I do not get enough fluids, I invariably wake up the next day with a pickaxe headache and they can linger on into the following day. The timing of fluids is important after surgery as you are too full to drink after meals and having fluids too late in the evening can cause reflux. It has taken me a while to work out a solution but I aim to drink 500ml of water, three times per day.

The point I am making here is, you have to be both creative and adaptable to develop and implement these types of workarounds in order to maintain a good quality of life.



**34. Yesterday, Today and Tomorrow (October 2018)**

This final sketch shows quite simply what oesophagectomy patients have had done and the uncertainty around the future. As I said earlier, there is no patient manual for this operation and everyone has different experiences, setbacks and food suitabilities.

There is plenty of support available from health professionals, cancer charities and other patients and with a certain amount of self-experimentation and bravery, day to day living can be good.

## Closing remarks

The incidence of oesophageal cancer has not really changed but it is still not very common in women and more people are surviving. Finding out you have cancer is shocking but if you are lucky to catch it early, quality of life can be good. Researchers are still a long way off being able to pinpoint, more accurately, who will get oesophageal cancer. The only weapon available to patients is being vigilant over symptoms and not relying on over the counter antacids without medical supervision. Stopping smoking, limiting alcohol intake, changing one's diet, eating smaller portions and losing weight can also help to address acid issues.

For health professionals, gastroscopy is the most accurate surveillance weapon of choice but it is expensive and unpleasant for patients. The cheaper and less invasive Cytosponge (a sponge on a string) developed by the Medical Research Council in Cambridge, is showing promise and is currently being trialled in a number of GP surgeries. This aims to detect early signs of cancer cells in the oesophagus and works in a similar way to cervical cancer screening.

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 symptoms of relevance were bouts of hiccups and the occasional hollow, hungry feeling in my chest accompanied by a cold rather than hot sensation – like the coolness of eating a mint felt within 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 gathered from the websites of Heartburn Cancer UK, the Oesophageal Patients Association and Macmillan Cancer Support. The presence of any of the symptoms listed below, especially the first one, should signal the need to book a GP appointment:-

- 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.

The final page is dedicated to online oesophageal cancer-related resources divided into

- Charities/Patient support groups
- Medical Societies
- Patient blogs
- Patient articles
- Patient books

The links overleaf were accurate at the time of publishing.

## Charities and patient support

Heartburn Cancer UK ([www.heartburncanceruk.org](http://www.heartburncanceruk.org))  
Oesophageal Patients Association incl patient forum ([www.opa.org.uk](http://www.opa.org.uk))  
Macmillan Cancer Support incl patient forum ([www.macmillan.org.uk](http://www.macmillan.org.uk))  
Ochre ([www.ochrecharity.org.uk](http://www.ochrecharity.org.uk))  
Guts UK ([www.gutscharity.org.uk](http://www.gutscharity.org.uk))  
Oesophageal Cancer Fund ([www.ocf.ie](http://www.ocf.ie))  
OG Cancer NI (<http://ogcancer.org>)  
Barrett's Wessex (<https://sites.google.com/site/barrettswessex>)  
Barrett's Day (<https://sites.google.com/site/barrettsday>)  
Barrett's Oesophagus Campaign ([www.barrettscampaign.org.uk](http://www.barrettscampaign.org.uk))  
Esophageal Cancer Awareness Association ([www.ecaware.org](http://www.ecaware.org))  
Esophageal Cancer Action Network (<https://ecan.org>)  
Esophageal Cancer Education Foundation (<https://fightec.org>)  
Pancare Foundation ([www.pancare.org.au](http://www.pancare.org.au))  
OCAGI ([www.ocagi.org](http://www.ocagi.org))  
Degregorio Family Foundation ([www.degregorio.org](http://www.degregorio.org))  
Esophageal and Stomach Cancer Project (<https://escproject.org>)  
OOSO (<https://ooso.org.uk>)  
The Gut Foundation (<https://gutfoundation.com.au>)  
Action Against Heartburn ([www.actionagainstheartburn.org.uk](http://www.actionagainstheartburn.org.uk))

## Medical societies

American Foregut Society ([www.americanforegutsociety.org](http://www.americanforegutsociety.org))  
Association of Upper GI Surgeons (AUGIS) ([www.augis.org](http://www.augis.org))  
International Society for Diseases of the Esophagus (ISDE) (<https://isde.net>)  
Society of American Gastrointestinal and Endoscopic Surgeons (SAGES) ([www.sages.org](http://www.sages.org))

## Patient blogs

Oesophagectomylife (<https://oesophagectomylife.co.uk>)  
The Cancer and the Quiff (<https://bjegreen.wixsite.com/cancerandthequiff>)  
My oesophageal cancer journey (<https://myoesophagealcancerjourney.wordpress.com/tag/esophagectomy/>)  
Chloe Bees Blog (<https://chloebees.home.blog>)  
A turn for the better (<https://aturnforthebetter.org.uk>)

## Articles

Thomas Keneally [www.theguardian.com/books/2017/nov/11/thomas-keneally-death-is-not-the-fly-in-the-cosmic-ointment-it-is-the-cosmic-ointment](http://www.theguardian.com/books/2017/nov/11/thomas-keneally-death-is-not-the-fly-in-the-cosmic-ointment-it-is-the-cosmic-ointment)  
Steve Hewlett's Guardian Columns [www.theguardian.com/media/2017/feb/20/steve-hewlett-broadcaster-and-journalist-dies-aged-58-cancer?](http://www.theguardian.com/media/2017/feb/20/steve-hewlett-broadcaster-and-journalist-dies-aged-58-cancer?)  
The History of Esophageal Cancer [www.sciencedirect.com/science/article/abs/pii/S0889855309000053](http://www.sciencedirect.com/science/article/abs/pii/S0889855309000053)

## Patient Books

Oesophageal Cancer: My Story by Jimmy Dean  
When I Die by Philip Gould  
Mortality by Christopher Hitchens  
Oesophageal Cancer: Your Way Forward by Dr Patrick Kingsley  
My Year with Cancer by Robert Paul Quinn

***“I loved the way you used your creativity to show  
your journey”***

***“Very moving work and so glad you found a way to do it  
and raise awareness”***

***“Beautiful art work. Very interesting and informative  
exhibition from a brave lady”***

***“This needs to be everywhere. Wonderful in every way”***

Feedback received from the “Art of Oesophageal Cancer” Exhibition  
on 29 May - 27 June 2019 in Warrington.

