

FOOD ISSUES FOR THOSE LIVING WITH ACHALASIA

5-7pm, Tuesday 3 March 2020. Hospital of St John & St Elizabeth

AGENDA

1. Update on Achalasia Charity from Alan Moss
2. Welcome from Andrew Gallini, Chief Nursing Officer at St John's and St Elizabeth's
3. Claire Donnelly, Dietitian at Whittington Hospital
4. Q&A with Majid Hashemi

A note on abbreviations

LES = Lower Oesophageal Sphincter, situated at the bottom of the oesophagus and opens into the stomach

PPIs = Proton Pump Inhibitors that reduce stomach acid, like Omeprazole.

GERD = Gastro Oesophageal Reflux Disease

ACHALASIA CHARITY UPDATE

Governance

- Achalasia Action is now registered as a charity (no 1187367) with 8 trustees, who have been working hard to put all the necessary legal and regulatory structures in place. Trustees are Amanda Ladell, Alan Moss, Majid Hashemi, David Holden, Neil Ham, Gavin Nash, Silvia Davey and Andrew Williams.
- Achalasia Action have a bank account and a fundraising page and can now legally raise and hold funds www.achalasia-action.org/donate-to-achalasia-action.html

Communication

- There is an Achalasia Action website (kindly created and managed by Neil) Really keen to get your personal stories, they are featured in the Support section www.achalasia-action.org/support.html Email Neil via the website if you would like to contribute a story to help other people who have Achalasia. You can also sign up to the mailing list on the website.
- There is a Facebook page please like, follow and comment – this will push it up the rankings and make it easier for anyone with Achalasia looking for support to find it www.facebook.com/achalasiaaction .
- The Twitter account is <https://twitter.com/AchalasiaAction> The Trustees are looking for a volunteer / volunteers to help with social media – could it be you? Please get in touch via the website. [Silvia has asked her friend Pilou to help]
- There are leaflets about Achalasia Action and copies of the Patients Guide to Achalasia – these will be refreshed soon but please take them to your medical appointments and clinics and share them with clinicians. Downloadable from the Info Hub on the website www.achalasia-action.org/information-hub.html or by contacting Alan Moss at alan.moss@achalasia-action.org
- The first meeting in Bournemouth took place on 26 January 2020. Planning more regional meetings to support people around the UK. [These and other meetings now taking place on Zoom for the duration of the CIVID-19 crisis]

Fundraising

- We have our first London Marathon runner, Kirsty Howe – trying to raise £1,000. Please share with your networks. You can find her details and [Go Fund Me fundraising here](#) and on the Achalasia Action Facebook group, [hoping for success when the London marathon eventually takes place].
- A Waitrose branch in Bournemouth will be collecting green tokens for Achalasia Action during March – tell anyone you know locally!

And finally keep an eye on the website and mailing list for the ACHALASIA ACTION launch party!!! (Delayed until further notice because of the Coronavirus)

WELCOME FROM ANDREW GALLINI, CHIEF NURSING OFFICER AT ST JOHNS' AND ST ELIZABETH'S

- This Achalasia meeting has been hosted by the hospital free of charge for 6 years.
- Andrew first came to work in the hospice, then moved to being Chief Nursing Officer
- The hospital has fantastic heritage, established by Cardinal Wiseman 162 years ago, set up by Sisters of Mercy who were working with Florence Nightingale in Crimea.
- 100 years ago, they built the chapel brick by brick in the hospital, so they now have an extraordinary Catholic chapel in the heart of the hospital. They are however very diverse and inclusive.
- The hospice is a charity, and is open to all NHS patients (this is where the donations at our meetings go) The hospital is private.
- The hospital has a wide range of specialities – 80% of admissions are surgical
- It's a particularly exciting time as they are undertaking a major new build. They currently have surgical theatres that are over 35 years old. The new structure will house 7 new theatres including 1 new endoscopy suite. It will also include a much larger urgent care centre, they currently have around 13,000 attendances a year.
- They are most proud of their nursing – getting fantastic feedback. Patients regularly rate nursing / quality of care as 98/ 99%
- Consultants recently rated the hospital 100% for the care given to their patients and BUPA rank it a top hospital.
- All present thanked Andrew and the hospital team for their hospitality.

CLAIRE DONNELLY - UPPER AND LOWER GI DIETITIAN, WHITTINGTON HOSPITAL

- Claire introduced herself. She is an upper and lower gastro-intestinal dietitian based at the Whittington hospital. She works with people with a range of conditions including Crohn's disease, various liver diseases, and those who have compromised nutrition for a range of reasons including oesophageal strictures (blockages which have a similar presentation to Achalasia)
- Claire works in Intensive Therapy Units (ITUs), on the wards, and with outpatients.
- She works with patients receiving nutrition in a variety of ways – orally (just eating!), through feeding tube directly into the gut and with intravenous nutrition (directly into the blood if the gut has failed)
- Claire stressed that there are no evidence-based guidelines around eating with Achalasia but she would apply her knowledge to signpost credible guidance. There's a possible space

here for Achalasia Action to work with dietitians to develop some evidence-based guidelines.

- There's a lot of nutritional misinformation in social media and the general press. Advice given by people without medical qualifications, not operating under a code of ethics and often with something to sell or another agenda. About 50% of her work with outpatients is supporting them to sort out fact from fiction and make good dietary choices. She sees her role as releasing this burden.

SOURCES OF INFORMATION

- Claire signposted three credible sources of internet-based support – people who are trained, qualified and operating within a code of ethics and evidence based nutritional advice.
 - Dr Hazel Wallace, The Food Medic, also has a strong social media presence - <https://thefoodmedic.co.uk>
 - Maeve Hanan – Dietetically Speaking <https://dieteticallyspeaking.com>
 - Research dietitian Dr Megan Rossi, The Gut Health Doctor, education hub with lots of useful resources including around supplementation - <https://www.theguthealthdoctor.com>
- And a book for no-nonsense nutrition education based on clinical evidence and written by two dietitians:
 - *Is Butter a Carb?: Unpicking Fact from Fiction in the World of Nutrition* by Rosie Saunt and Helen West

PROBLEM FOODS

- It is challenging to filter out the nutritional nonsense and Claire reminded us that everyone responds to food in different ways.
- If you haven't already, Claire recommends keeping a **food diary** – and see if there are any patterns that emerge or links with between food stuff and pain.
- It's difficult to design an effective clinical trial (because everyone responds differently) which means that clinical evidence is limited. There's no one size fits all. It's a journey to work out what works for you.
- Claire asked if **peanut butter** was difficult to swallow – most people didn't have a problem.
- **White bread** – seems to linger / congeal for lots of people and be very slow / uncomfortable to swallow.
- There was a question about what foods to ignore to minimise possible **fermentation** in the oesophagus (from food that might sit there for a while). There was no clear answer to this. Many processed foods probably wouldn't ferment but aren't as nutritionally valuable. In absence of evidence trying to minimise the risk of food sitting around for a long while. Eating **little and often** is the suggestion.
- Foods that seemed to stick for a lot of people - **Bread, rice, pasta, meat** (incl. **chicken**), **tuna**
- There was a question from the room about being advised to eat our **vegetables al dente** – if we overboil veggies does it make a significant difference to the nutrition? Claire suggested that if you do have to have veggies very soft, think about **soups and stews** so you can also consume the water that the vitamins leach out into when cooking the vegetables. Some veggies are better than none so give yourself a break (Also, don't listen to chefs who often have a terrible diet!)

- One person present lives in a region with stunning local produce and although has Achalasia, and eats all and any meat, by **slow cooking or braising** it to get a consistency that is good and soft to swallow. Meat can also be minced in a shepherd's pie with gravy etc.
- Claire said that you can make your own **smoothies** using protein powder or yoghurt or milk or nut milks or ice cream (whatever your protein preference is!) and fruit and veg if swallowing is tricky.
- If **custard** helps puddings go down, eat pudding with custard! If your weight is stable exercise moderation. Eat it, enjoy it and apply **common sense**!
- Claire noted that if weight loss is an issue, adding butter, cream and and oils can increase the **calorie intake** eg adding butter in mash potatoes.
- The benefits of **olive oil** are supported by strong research evidence on **Mediterranean-style** diets. Make it your 'go to oil' for cooking. Coconut oil is not supported by research evidence currently, and again has been over-hyped by commercial marketing. Best to use it infrequently.

SWALLOWING DELAYS

- A quick reminder - in a healthy person a swallow of food takes seconds to get from mouth to stomach. The food passing through the back of the throat is the trigger for the LES to open, in Achalasia patients this mechanism doesn't work well / at all. More than 10 seconds from mouth to stomach is a **delay**.
- Sometimes the remains of stuck food can appear 72 hours after the patient has eaten so it can be difficult to determine what was the trigger.

SUPPEMENTS, VITAMINS AND MINERALS

- There was a question about the effectiveness of **supplements**. Claire said these are not the answer to everything and supplementation should follow screening and advice from a doctor. **Blood tests** can check B12, Iron, Calcium etc and then any necessary supplementation can follow. She advised against taking vitamin and mineral supplements ad hoc.
- There were a range of experiences at the meeting, from people who found it easy to access a blood test to test nutrition levels and follow up support, through to those who found it more difficult.
- **Vitamin D**. The guidance since 2010 is for the population to take 10 micrograms of Vitamin D SUPPLEMENT daily during the winter months. Read the NHS Guidance www.nhs.uk/news/food-and-diet/the-new-guidelines-on-vitamin-d-what-you-need-to-know/ It can be taken in tablet or spray form. Vitamin D is found in a very limited range of foods – hence the advice on supplementation in the winter months when there is limited sunshine.
- One person reported that they have noticed **Vitamin D** seems to have an impact on their **spasms**. They take the supplement as an oil that they hold in the mouth for a few seconds. If they forget the oil, their spasms get worse.
- Latest clinical evidence suggests that vitamin supplements (when there is no clear clinical need) don't reduce disease (despite what is suggested in the media / adverts and marketing hype!). Bear in mind the composition of vitamin and mineral supplements differ from how these micro-nutrients are naturally found in 'the food matrix'. It is better to focus on your food.

- If your blood results show you are deficient in a vitamin or mineral, your medical team will provide the relevant supplementation.
- A note on **B12**, which is only available from animal products (meat or dairy). If you are vegan you may need to supplement with B12. You can ask your GP for a blood test to monitor your vitamin B12 levels to check if you do need to supplement.
- B12 is also available in food like fortified breakfast cereals eg **Ready Brek**. **Nutritional Yeast** is also great and can be added to dishes (it's a bit Marmite, ie people love it or hate it). **Algae** supplements can also provide B12. These come in powder form to add to smoothies.
- Recommendations from the room: One person uses pre-prepared **Weetabix drinks**, you can buy from the supermarket. Also a fortified cereal but in a drink format. One person uses an algae-based powder, Dr Schulze's, mixed with fruit juice or water in the morning (has an acquired, grassy taste)

SUGAR

- There was a question about **Supplement drinks – are they too sugary?** According to Claire there is a time and a place for nutritional supplements, for example when trying to regain weight after illness, when the focus is on optimising nutritional status. After recovery, it is best to focus on 'food first'. There was a recommendation from a group member for **Fresubin** designed for people with dysphagia, available on prescription though some people find it difficult to get prescribed. [There will also be other equivalent drinks under different names].
- Claire noted that sugar itself doesn't cause diabetes directly – but increased weight can cause metabolic changes and **insulin resistance** – it's a complex biochemical process and not a clear sugar = diabetes equation

Claire was happy to share her email address, but unless you were her patient she couldn't offer specific guidance. **DONNELLY, Claire (WHITTINGTON HEALTH NHS TRUST) <claire.donnelly2@nhs.net>**
 Claire was thanked most warmly for her very helpful advice.

MEDICATION

- Is there any **medication** we should avoid if there is slow transit through the oesophagus? A tablet sitting in the oesophagus for an extended period could cause ulceration (because it's designed to be released in the stomach). If you have to have it in tablet or capsule form – avoid taking it straight after eating, take with lots of water. Lots of pharmacists will be able to provide medicines in liquid or powder form, but not all medicines will be available like this. Discuss with your prescribing doctor and the pharmacist.
- The most commonly-taken pill by Achalasia patients is **Omeprazole**, or other PPIs (which are often best taken half an hour before eating – but check the instructions carefully)
- There was some discussion around **PPIs**, which are a very commonly prescribed and safe medication but have side effects, including insomnia, inhibiting vitamin uptake and stomach pains. Mr Hashemi wanted to encourage people to be really sure that they require them, eg after a pH test that confirms increased acid in oesophagus or the presence of GERD. The gut needs acid as part of its normal functioning and we should ensure that we really need medication that suppresses this.

- One person present has weaned off PPIs, uses **Gaviscon Advance** to manage occasional symptoms and follows a diet to minimise the production of acid eg less alcohol, spicy food and caffeine
- Mr Hashemi rates Gaviscon for many situations. It's inert and has limited side effects while dealing effectively with the symptoms.

GENERAL QUESTIONS AND ANSWERS

Question: What causes pain at the LES sphincter area?

Answer:

- The pain you feel in the oesophagus is very difficult to localise. The pain is diffuse. Because you feel the pain at the lower end of the sternum doesn't mean the problem is there as pain can be 'referred' elsewhere through the nerve system.
- The cause could include either mechanical aspects or be caused by acid reflux.
- You cannot press the LES because it is behind the breast bone – you can't feel it. The liver is also nearby, as well as body fat.
- The room shared physical tips for dealing with **spasm pain** – tapping on the chest like a gorilla, tapping along the bra line on the back. Stretching can help progress food downwards, hands / arms up in the air. Other stretch moves – push chest forward, hand above head, make fists and pull down with raised elbows. Someone finds massage along either side of the spine helpful.

Question: Whilst cooking dinners/soup, pain comes on before eating – could it be caused by gastric juices?

Answer:

- Answer is difficult as we still don't have enough evidence of research. A lot of gut hormones we don't know about. For example, Ghrelin, a gut hormone related to peptide, only became widely known 15 years ago. There is no evidence about how this affects achalasia. There are many gut hormones being secreted in the gut, in response to food or hunger, and they may or may not affect the oesophagus - we don't know enough about them. It would be interesting to study this in a group of patients.

Question: What is the best way to proceed if fundoplication fails? The last endoscopy showed the fundoplication disappeared.

Answer:

- Diagram drawn of the stomach and oesophageal sphincter. Explained how the top part of the stomach called the fundus is wrapped around the oesophagus to protect it. A partial fundoplication is often as effective as a full fundoplication. But it's a difficult operation to do, and to get right, and there are a lot of options that surgeons can do. Best to do a minimal dissection, and keep natural anti-reflux mechanisms. If they can't see fundoplication in the endoscopy, it means that the fundoplication could have loosened up, or is very minimal. Majid thinks it is very important to follow up patients yearly to ensure the fundoplication is still in place, and is prepared to operate again in appropriate cases to control the reflux.

- If people have reflux problems, then they need to really understand if PPIs are the right options. And if the reflux is really bad, then surgeons can re-intervene for reflux and revise the fundoplication, without needing to revise the myotomy. But this is not an easy fix, and it is important to investigate thoroughly and collect evidence about its effectiveness. The first operation is the easiest, and it's important to get it right when the oesophagus is free of scar tissue, which then makes surgery easier.

Question: What is the oldest patient you can operate on?

Answer:

- What is important is the physiological age of the patient, rather than numerical age.

Question: What is the most common fundoplication?

Answer:

- 360 degrees is easiest. 270 and 180 degrees is more complicated. They can be down to 120 degrees. The original myotomy did not have fundoplication. But then surgeons started doing them 20 years ago. The type of fundoplication depends on the surgeon and their experience. It also depends on the patient, and it needs to be tailored to the patient's fundus. The wrap can be around the back of the oesophagus or round the front.

Question: What happens after the POEM in terms of reflux?

Answer:

- There is no anti-reflux mechanism for the POEM, so reflux would have to be treated with medication, in the form of PPIs.

Question: What is the difference between POEM and a conventional myotomy?

Answer:

- The POEM will involve an endoscopic instrument being passed through the mouth /nose, and a cutting of the muscles inside the lining of the oesophagus. A conventional myotomy involves laparoscopic / keyhole surgery. Both will be doing a cut in the oesophagus, but the POEM does not do a fundoplication. The other difference is that POEM avoids the five cuts in the abdomen. POEM still doesn't have long term data for acid reflux control.

Question: Is there a cure for achalasia?

Answer:

- No. Everything is directed to relief of symptoms.
- One of the most worrying aspects is the risk of laryngeal and lung infections, as they can very negatively affect a patient.

Question: What determines whether you get the dilatation or surgery?

Answer:

- Data shows that dilatation is quite effective, and some data shows it is as effective as surgery, but this is less strong evidence.

- It is much harder to do a good myotomy as a surgeon on patients who have had multiple dilatations. It's not wrong to have dilatation first, but one needs to decide why. If you are young and fit, and want symptom-free years ahead, then you might want to go direct to more definitive surgery. The effectiveness of a dilatation can decrease with time. The conversation included mention of a good surgeon colleague in Homerton Hospital, Mr Yashwant Koak.

Question: Should I be worried if my surgeon isn't following up with me.

Answer:

- Decisions are often made on an individual case by case basis. If symptoms worsen, then you should revisit the surgeon.