ACHALASIA ACTION
www.achalasia-action.org
Reg Charity no 1187367
Uniting for a rare swallowing condition

Achalasia Action Patient Support Meeting 4th May Via Zoom

Achalasia: Keeping your oesophagus as healthy as possible

Alan Moss, Achalasia Action Chairman, welcomed everyone to the meeting and introduced the panel:

- **Majid Hashemi,** Upper GI Surgeon and Clinical Chair of Achalasia Action
- **James Brewer**, Surgeon for Complex Benign Upper GI Issues from Chelsea & Westminster (standing in for Sach Kumar)

The panel answered a series of questions that had been notified in advance and attendees were able to put additional questions to the panel via the zoom meeting chat function.It was noted that we can only give generalised answers and cannot give medical advice to individuals about their personal treatment.

Whilst we keep these sessions free of charge, we do appreciate donations which can be made through our website www.achalasia-action.org. We are dependent on donations as our main source of income to enable us to run meetings and the helpline, produce information booklets and leaflet etc.

We are launching a new improved website soon, and hope this will provide a valuable source of information and an improved means of communication for the achalasia community. Please send any questions and sign up to the newsletter.

Q & A Session
Based on questions submitted in advance with added questions from the chat.

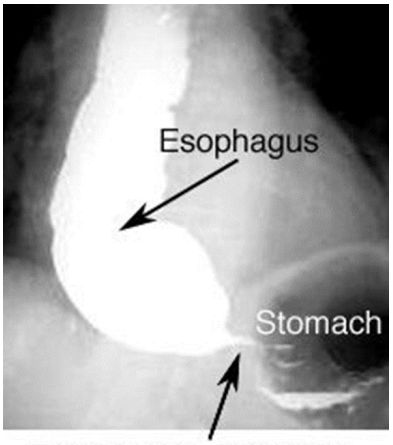
Belching and Bad breath

Q: *Is it normal to have increased burping? I did not uses to burp but now I do, and it helps clear blockage [not clear whether this is after surgery or not]*

Q: *I think my breath is starting to smell – is this normal?*

A brief explanation of Achalasia was given by James Brewer to provide context to this and other questions to follow:

Your oesophagus is a muscular tube connecting mouth to stomach and it has a way of pushing food down in a very organised manner - peristalsis. Most people can even swallow upside down because the muscles squeeze down in such a coordinated manner. When it gets to the bottom where it connects to the stomach there is a valve (the Lower Oesophageal/Esophageal Sphincter or LOS/LES) which prevents reflux of the stomach contents. This valve should open naturally at the end of the swallowing process to let the food bolus through into the stomach as the muscles of the LOS relax in a coordinated manner. In achalasia this last relaxation starts to be impaired and gradually gets worse so that food starts to stick and will start to stack up above the LOS which does not open properly to let food through. Over time the oesophagus continues to try to contract against this resistance but eventually gets tired of the resistance and loses its ability to contract in a coordinated way. It then loses natural tone, and as there's always food and drink at the bottom of the oesophagus it becomes dilated. Over time this develops into what has been described as the bird's beak anatomy, dilated oesophagus and narrow, tight LOS which can be clearly seen on a barium swallow image.



Esophageal Achalasia

So to answer this question:

A: When achalasia has developed, the congestion leads to a build up of saliva and food/drink in the bottom of the oesophagus which can then come up as regurgitation.
In a baggy oesophagus this can lead to a feeling of wanting to burp in an attempt to evacuate the contents from the gullet.
The fluid sitting in the oesophagus that has not passed through the LOS can come back up into mouth especially if lying flat. This is often labelled as reflux but shouldn't be confused with acid reflux which comes from the stomach. It is refluxing / regurgitation but of fluid that has been sitting in the oesophagus - ie whatever you have been eating or drinking that is undigested. This can have a bad smell or taste as it has been sitting in the oesophagus for a while stagnating/fermenting.
Check other causes of bad breath such as problems with teeth as the tooth enamel can be affected.
If it's achalasia causing the problem then aim to remove the blockage with treatment.

Note: After fundoplication some people have found that belching can be difficult but it should be possible if the wrap isn't too tight.

Pregnancy and Childbirth

Q*: I started achalasia symptoms four months after childbirth. Has any connection been made about pregnancy or childbirth activating achalasia symptoms?*

A: It's not clear what initially causes achalasia ie no single cause has been identified. As described above it is the lack of relaxation of the final part of the gullet,so the LOS, which forms a connection to the stomach, doesn't relax in a normal manner when you swallow. This seems to be caused by the nerves in this area not working as they should. One theory is that it could be an autoimmune response following an infection or infective insult but this is not 100% clear. Can pregnancy cause this? Pregnancy physiologically increases the intra abdominal pressure and is known to exacerbate the presence of an hiatus hernia for example so will also affect the way the LOS behaves. However whilst this may exacerbate pre-existing symptoms of achalasia (whether diagnosed or undiagnosed) there is no evidence that pregnancy or childbirth actually causes or triggers achalasia.

Majid asked James and female attendees whether they have made any link between the menstrual cycle and flare ups that could be caused by hormones? Some attendees reported a link of flare ups to menstrual cycle so there may be a hormonal link.
We also know there is a link to stress which exacerbates symptoms or how symptoms are felt which may also be relevant when looking at achalasia in relation to big life events like childbirth.

Chat Q: *Would you recommend having surgery before being pregnant?*

James: Probably yes as it would help to maintain nutrition but make sure you have a wrap as otherwise could get bad reflux which pregnancy makes worse anyway.

Chat Q: *What does research show re patients becoming pregnant after having a Heller Myotomy?*

Majid: I would never tell patients to avoid becoming pregnant either before or after surgery so long as the achalasia isn't so severe that you are not able to get sufficient nutrition. No problem after surgery either. There may be worsening of symptoms such as reflux but this will be temporary.

Chat Q: *Is there a link with endometriosis?*
A: None that they know of but this is a disease with some autoimmune features so there might feasibly be a link. Three women reported that they had suffered from endometriosis in the Chat. [There were up to 70 men and women on the call in total]

Exercise

Q: *Is it safe to do exercise with achalasia, eg weights, dance classes,walking?*

Q: *Are abdominal exercises good or bad for achalasia? How to avoid loss of muscle tone, especially round abdomen.*

A: Depends on your current situation - e.g. have you been formally diagnosed/ had any treatment or awaiting operation? Upper GI surgeons would want to assess what your abdominal physiology is like, what is the pressure in your abdominal cavity and your thoracic cavity. Anything that increases the pressure can have an impact on how your oesophageal junction works and when we do anything very intense or requiring effort we are also increasing the pressure in our thoracic cavity. Patients with achalasia tend to have a very distended and lazy oesophagus which accumulates a significant volume of fluid and when making significant exertion this can be pushed upwards as the pressure in the abdominal cavity exceeds the external pressure and this can result in reflux or even volume regurgitation due to the accumulated liquid going into your throat or mouth.
So can you exercise, and are there any limits? Exercise is beneficial and you don't necessarily need to avoid it but you would be wise to take these factors into account, depending on your situation and recognise that the pressure resulting from exertion can affect your experience of reflux or precipitate regurgitation. So know your own limits, take it easily and build up slowly. Toning exercises are especially good.

Chat A: People contributed their own experiences of exercise including running 25 kilometres, and the benefit of gradually building up training levels and tolerance over time. Fear can be a big issue. Some in Chat said that they took antacid pills before exercise.

Candida

Chat Q: *Advice on cause and treatment of coated tongue in my 12 year old*

Candida can result from food sitting in the oesophagus as the both oesophageal flora and the natural protective barrier change when exposed to food and fermentation and decomposition of saliva - so this is one of the risk factors for developing over infection with opportunistic pathogens like candida albicans.
Problems can occur if patient gets candida oesophagitis rather than just on tongue. Can cause bad heartburn and worsen swallowing for example.
Could get swabs from tongue or throat and treat with antifungals but need to assess how likely it is that oesophageal candida is present and if treatment is worthwhile.
This question related to a 12-year-old so the panel wouldn't want to endoscope them or recommend treatment without consulting a paediatric specialist such as Mohamed Mutalib from Evelina Children's hospital. [Since the meeting Dr Mutalib has confirmed that candida is not uncommon when saliva and fluids do not flow properly through the oesophagus. Sometimes treatment for thrush will not be effective and the patient will need systemic antifungal therapy. The diagnosis will require endoscopy]. If there are symptoms of candida, it does need to be treated. If it is in the oesophagus itself it may not always be visible except with an endoscopy.

Diet

Q: *Should people with achalasia avoid acidic foods, as they may linger in the oesophagus – or any other foods for that matter?*

A: Nothing you eat is more acidic than the stomach acid, so acid levels in food are not likely to have much effect in comparison. Not a problem if oesophagus is clearing food normally, but if you have repeated regurgitation then avoid food that might cause irritation foods eg spicy foods.
Pre surgery advice to maintain nutrition and weight is to go for things that you know will go down like protein shakes, soups, with high nutrition content.

Q: *Are there any specific foods, herbs, spices etc that we should use for oesophageal health, looking after the lining etc? eg honey,blueberries, turmeric?*
A: Gaviscon can help in terms of coating the oesophagus but there's no strong evidence that any of these anti-inflammatory food have a positive effect on oesophagus.
Majid has heard anecdotally that cumin tea or oregano can help.

Timing of meals is very relevant - don't eat in last 3-4 hours of day to avoid aspiration or regurgitation in the night. Especially important pre treatment.
Pre and post surgery it's best to avoid foods that can coagulate and get stuck like rice and bread, stringy foods etc. Medication in form of pills can be a problem.
There is lots of information and tips on diet on the website and our booklet *Living with Achalasia*

Timing of surgery / treatment

Q: *After diagnosis of type 2, is it detrimental to oesophageal health to delay Heller Myotomy surgery if offered it?*
A: James: Most patients present to specialists with about 3 years' experience of symptoms of some kind. Timing/ delaying depends on discussion with surgeon and expectations addressed. If symptoms are mild, one can delay and manage with modified diet. Ultimately surgery is an undesirable act and shouldn't be taken lightly. If symptoms are severe seek the right team and intervention.

Q: *Would a delay mean less chance of a successful outcome?*
James: Success not necessarily affected by delay.
Majid: Delay can lead to worsening of a baggy oesophagus. Also consider the effect on general health eg if vocal cords and lungs are being affected by reflux/ regurgitation and this may indicate not to delay treatment. First treatment is your best shot at a good outcome so make sure the first treatment is a good one and not delayed if symptoms are severe.

Repeat Operations: If patient is considering a re-do treatment such as a repeat myotomy you should first thoroughly explore what is causing the symptoms eg if suffering reflux you may just need the wrap adjusting and not repeat a myotomy which itself may be fine. Make sure repeat surgery is really necessary and that, as with any surgery, there's a clear-cut target for outcomes.

Support

Chat Q: *How can people who have had multiple procedures over years access support, eg those who have had a myotomy but are still not symptom-free. Not all about surgery.*

A: There is little support out there, as shown by a study carried out by Melika Kalantari as part of her PhD, and this is why this support group is so important. Dietitians can help but will probably not have a special interest in achalasia.
This meeting has been a bit surgery-focussed but these meetings usually deal with issues like how to live with achalasia, manage symptoms, diet tips etc. Information on the website and in our publications can help. Body, mind and lifestyle approach - eg trying to avoid stress and tension and certain foods has a big effect.

Aspiration

Q: *What kind of things should one do to keep the oesophagus healthy, and keep airways clear if one has lost **all** oesophageal motility?*
***Q**: Are there any techniques one can learn to try and keep lungs working well and to avoid aspiration?*

A: Refer to James' explanation above regarding the role of physiology and pressure in achalasia symptoms: One key thing is timing - ie timing of eating in relation to exercise and sleep to avoid regurgitation/ aspiration. Exercise is good long term - especially toning exercises and resistance training, not so much high intensity exercise. Should aim to create muscle bulk and increase tone.

Q: *Is aspiration whilst asleep normal? I'm sometimes awoken and can't breathe. It's quite scary. I believe its due to aspirating regurgitated liquid*

A: Majid: It's common but shouldn't be the norm, so you need to seek advice and possible treatment. It's recommended that you avoid lying too flat when sleeping ie by using a wedge pillow or raising head of bed - this can help avoid reflux/ regurgitation. Some people in the Chat supported the idea of sleeping with a wedge pillow

Q: *Can achalasia cause **upper** oesophageal sphincter problems. I've started to experience issues with swallowing tablets/food and it going down the wrong way. [Upper Oesophageal sphincter is a flap that directs food into the oesophagus rather than into the trachea and lungs]*

A: Tablets not going down may just be related to achalasia.
Patients may experience a slight spasm in the neck while swallowing which can be a reaction to regurgitation and the upper oesophageal valve can become weak over time.

Reflux

Q: *I have achalasia type 2, and had Heller Myotomy with wrap a year ago.
I eat a low acid diet, sleep on an incline, take an H2 blocker, use Gaviscon Advance aniseed, drink alkaline water and stop eating at 7pm but still have a burning tongue and mouth as soon as I wake up and eat or drink, and it lasts all day. I am awaiting endoscopy and barium swallow. Is there anything else that could be going on beside just reflux? Anything else I could be doing?*
A: Needs to be fully investigated if symptoms have not resolved

Q: *6 months after POEM I no longer have reflux symptoms. Could I have silent reflux?*
Yes, could be - or aspiration

Q: Are 24 hour pH tests reliable?
A: Yes

Distended oesophagus

Q: *Is there any way to stop the expansion of the bottom of your oesophagus? I have had this condition for 30 years and want to know how to manage it so I don't end up with medical complications as I grow older.*

Q: *I am pre-surgery. I have had the symptoms of achalasia since 2014 and was diagnosed in 2021 with Type 2 achalasia. If my oesophagus has been stretched and misshapen by food and drink sitting in it, how does this affect my outcome following surgery? Can surgery (or any other treatment) help to regain a proper shape for the oesophagus?*

A: Majid: No, the shape of the oesophagus will not be regained but treatment may prevent further worsening.

Q: *I remember 'bird's beak' barium swallow image and loose, expanded oesophagus above. Does it remain in this shape after Heller myotomy? Anything I can do to stop it going out of shape other than small portions of food?*
Q: *My question is related to the 'bird beak' constriction & loose expanded oesophagus above. Mine was really wide & easy to see when imaged. Post Heller's Myotomy I assume that the oesophagus stays like this , so that even if food is swallowed well it can stay around & not drain into the stomach if not the right texture. So small portions are best to avoid this happening. Is there anything else I can do which might help?*

Majid: After surgery there won't be the bird's beak as valve is no longer tight - bird's beak anatomy is seen in untreated achalasia. Refer to other responses re reduction of stress, relaxation techniques, sensible level of exercise and avoiding problem food. Anything that reduces stress will help. Needs to be done long term, persist at it.

Hiatus Hernia

Q: *Advice on treatment if I have hiatus hernia and achalasia?*
Q: Chat: *How can a hiatus hernia, or sliding hernia impact on a post op achalasia patient, and what , if anything can be done to help the impact? (there seems to be a trend in NHS to not perform surgery on hiatus hernia, but might there be a benefit in achalasia patients?)*

A: Patients with hiatus hernia should avoid having a POEM without repair of the hiatus hernia first and a fundoplication. In POEM the sphincter is disabled but still exposed to negative pressure due to the hiatus hernia, which will lead to significant reflux. It's already known that patients have more reflux with POEM than with Heller's Myotomy plus wrap.

How long do benefits of Heller Myotomy last?

Q: *I am a 26-year-old female who has undergone a robotic laparoscopic Heller Myotomy with a DOR fundoplication when I was 24 years old. How long does this procedure typically relieve symptoms for patients?*

A: James: Research shows that there is on average 80% control of symptoms and improvement for 5-6 years

Majid: Note that the operation is exactly the same whether done by robot or surgeon.

Q: *What are the recommended intervals for endoscopy screening /surveillance?*

A: There is no standard recommendation / formal guidance but patients should have yearly follow up in clinic and undergo an endoscopy if new symptoms present. Some recommend a barium swallow every 3 years to monitor the oesophagus.

Q: *Can other methods of 'screening' be used eg MRI scans?*
A: No, they are not so effective for this.

Complications

Q: *I am aged 68 and in good health, but started to experience difficulty in swallowing in 2021. Endoscopy showed a slight 'corkscrew oesophagus' (have not yet had a barium swallow, or manometry). Doctors plan botox at 6 month intervals to relieve strictures, and if this fails go for POEM (despite being PPI intolerant). Does botox damage the oesophagus and have any implications for future surgery?*

Majid: Yes it can and botox does not give lasting relief. May help for initial 6 months. Botox also makes future surgery more difficult.

Q: *I have several diverticula (pouches) two of which have been reduced with septotomy surgery. How can I prevent remaining diverticula stretching and causing further problems?*
A:James: A pressurised oesophagus can develop weak spots and form pouches, but he has no experience of it.
A: Majid: Pouches not necessarily related to achalasia in his experience.

The Role of Oesophagectomy

Q: *I've been told after two failed dilatations that having an oesophagectomy would solve all my problems. It is difficult but I am not losing weight. Is an oesophagectomy really necessary at this time?*
Q: *I've been told I'm 'end stage' achalasia and have a year to decide if I want my last op and that 4% (!!) die during surgery*

A: Majid: Majid pointed out that the risk of dying during the surgery for benign disease is probably 0% but way less than 0.5%. However, you should make sure you know why oesophagectomy is recommended and investigate whether it's a problem that could be solved with further less extreme surgery like a myotomy.

Majid asked James for his views on the role of oesophagectomy in treating achalasia and what factors surgeons take into account when this might be on the cards.
James: Oesophagetomy could be considered one of the biggest operations the body can take as it's a very large procedure and takes the best part of a year to recover. I don't think it's an answer to even "end stage" achalasia. What is end stage achalasia? Is it achalasia that's been treated several times and failed - if so we would need to individualise each case and discuss other options before considering something as radical as an esophagectomy. Need to consider that the persistence or worsening of symptoms could be a result of the original surgery going wrong and it may be possible to correct it. Things can be revisited/ reviewed e.g. can have a myotomy after a POEM, or a cardioplasty.
Cardioplasty explanation: tries to rectify the normal angle of where the stomach meets the valve by bringing part of the stomach back into contact with the oesophagus, bringing it into line and opening it up. Problem can be reflux as there is no longer a valve, the stomach is open, but still better than an oesophagectomy.

Majid: Made two points:
1. Why is it called end stage? This seems to be a circumstance where the treatment defines the disease - ie you call it end stage because you do an oesophagectomy rather than because the disease has an end stage as such. Following on from this Majid suggests we should instead be calling it 'refractory' as with other diseases which haven't responded to treatment.
2. Majid has only seen a handful of cases where an oesophagectomy has been performed for benign disease - a very small percentage of cases, less than 1% - which is why he is reluctant to discuss it as an issue in this forum. In the small chance someone does get recommended for an oesophagectomy you should only do it after meeting experienced specialists such as James and team or Majid to consider all the options, because the reasons previous treatments have failed are varied and can be fixed in the vast majority of cases. Get a second or third opinion.Get your test results and keep them on a disc for second opinions.

A: Chat: "Long term management is a challenge for a few of us, but high impact. I feel it is a whole body / mind / lifestyle approach."
"There may be benefit in improving support for those who have struggled for many years, sometimes with multiple surgeries, to improve management of the condition when further surgery is not a prospect".
"As someone having had an oesophagectomy, it's a last resort and not something to enter into lightly. As medics have said - it's a big op with lengthy convalescence"