



Research Update and Open Forum 9 November 2022, by Zoom

Meeting chair: Alan Moss, Chair of Achalasia Action Charity

**Medical Panel: Majid Hashemi, Consultant Surgeon
Sacheen Kumar, Consultant Surgeon
Catherine Rabess, Dietitian**

Research Update:

Melika Kalantari: University of Reading

Melika has completed a research project on living with achalasia and has designed a workbook dealing with how to make changes to help with eating in a social or unfamiliar setting. This is now being trialled and volunteers are needed to try out the workbook, which involves doing a pre and post intervention questionnaire possibly followed by an interview. Volunteers should have a diagnosis of achalasia, can be pre or post treatment, must be living in the UK and not have been involved in developing the questionnaire.

Contact Melika if you are interested in helping: melika.kalantari@pgr.reading.ac.uk

Majid thanked Melika for her work over four years on this unique qualitative research study. Achalasia Action especially welcomes research which seeks to help achalasia patients living with the condition day to day.

Medical Treatment of Spasms: (Development from our earlier spasms survey, with Stefan Antonowicz, Imperial College)

Achalasia Action are keen to support a project looking at how we can treat spasms/ chest pains as this has been one of the most recurrent themes raised in meetings and is one of the most difficult symptoms to live with, to diagnose/categorise and to treat. We have been working with Stefan Antonowicz from Imperial College on this and one of Stefan's colleagues has undertaken a review of all the written material on achalasia which concluded that there was not much recent or relevant written material on achalasia. In particular there is nothing on spasms and as clinicians vary in their treatment a proper clinical study of how to treat spasms is needed. This will firstly categorise spasms, secondly recruit volunteers and finally trial treatments; there are several options for treatment. This will be carried out in several locations - by Stefan at Imperial but also Sacha Kumar at Royal Marsden. It will take around a year to get everything in place and get the project up and running.

A previous survey conducted by Amanda Ladell for Achalasia Action included 57 people and they could be asked to participate.

I-PASS Study - Patient outcomes: Prof Giovanni Zaninotto and Sheraz Markar, Imperial College.

This is a study on patient outcomes and will include those going through a course of treatment but also patients who have not had treatment.

To participate contact Sara Jamel at Imperial College S.Jamel@imperial.ac.uk

OPERA study (Jonny Neville: University of Southampton): Children with achalasia

The OPERA study is being undertaken by the Trainee Paediatric Surgeons network led by Jonny Neville at Southampton University. It is trying to work up common themes in children who suffer from achalasia.

We would like to hear from parents of children with achalasia or adults who developed achalasia as a child who are willing to participate in this study.

Please contact Amanda Ladell: amandaladell@achalasia-action.org.uk

Dr Mohamed Mutalib, consultant gastroenterologist from Evelina Children's Hospital and his clinical nurse Emily White have been involved in research into the treatment of achalasia in children across the UK and may have some valuable insights that will help the OPERA study. (Amanda will put them in touch)

European Study on patient experiences, starting with children

The European Achalasia Group is conducting a study, called Ernica, for parents of children with achalasia and are looking for our support. Further details to follow.

Conor McCann: Stem Cell Research

This research was started but has paused at the moment due to funding. We would like to see this continuing as it seems the best long term prospect for a cure/ better treatment.

Open Forum - Q & A session

Water with meals – and follow-up

Q: Following dilatation almost two years ago, I have been able to swallow well. However, over the past six months I have found that I need to drink water ++ when eating to make the food go down. If I eat a meal, I often go through a litre of water, adding to what I need to drink throughout the day, often totalling four to five litres. I know drinking plenty of water is good for us, however I am also aware that taking too much fluid can be problematic. Do you think it's time to see my consultant again, and if so, what do you think they can do for me if actual swallowing isn't a problem?

A: Majid: Yes I always recommend a follow up after any treatment, not necessarily barium swallow or gastroscopy if asymptomatic but an annual clinical follow up. In the meanwhile there is no problem in drinking a lot of water.

Candida

Q: Is candida (thrush) a common symptom of achalasia?

A: Majid: Oesophageal Candida is not a direct symptom but can be a fairly common associated problem. This is due to food being held up in the oesophagus and as with any similar condition that causes stasis can lead to immuno-suppression and damage to the mucosa because of the fermentation of food, plus if you are a bit under nourished, run down or have been on antibiotics due to aspiration pneumonia - all these things can lead to a risk of candida. It's easy to treat (though the side effects of the antifungal drugs need to be monitored) but hard to diagnose without an endoscopy (sometimes possible to get a clinical diagnosis based on symptoms and mouth swabs).

Pains and Spasms

Q1: I have spasms regularly, especially at night. Are there any new treatments in the pipeline?

Q2: What further research into the cause of achalasia chest pain has taken place?

Q4: What are the best treatments for managing chest spasms?

A1& 2 & 4 : There are no new treatments at the present time in fact we're still using the same treatments as have been used for the past 20 years and going back to some old ones like GTN, nitrates, calcium channel blockers, buscopan. However research is planned into causes and potential treatment as noted above (Research project by Stefan Antonowicz)

Most important thing with spasms is to make sure there's not an obstruction, e.g. failed myotomy, scar tissue, or is it painful reflux - e.g. following a POEM. If not those two things then consider medical treatment for spasms. If spasms are especially at night this suggests reflux.

Achalasia Action have produced a lot of advice on how to eat better to avoid or manage spasms and what might help when you have one - see Living with Achalasia booklet, available on the website. It has been suggested that cannabis/ CBD might help but no research on this to date.

Q3: Could air trapped in a baggy oesophagus be a likely cause because of the belching that often comes with it?

A3: Trapped air is not the likely cause of spasms

Q5: Basically I've got my horrible claw-like sharp pain back again after 3 years of it calming down. My family and friends just say, "Take a paracetamol" So I try to explain that it doesn't work and help. But why is this ?? Is it that the nerve path is different or it's food stuck possibly - I'm never sure!

A5: Seek further advice from your consultant if symptoms have changed or returned. Pain travels through the nerve system which runs through the spine, so the approach should be to try to identify the source of what is actually causing the pain.

Progression of Achalasia

Q1. If a person has zero motility in their oesophagus prior to LHM (Laparoscopic Heller's Myotomy), by opening the Lower Oesophageal Sphincter (LOS) and food then being able to enter the stomach what deterioration can happen from there?

A1: Untreated achalasia may progress but if a successful/ complete myotomy has been performed there shouldn't be a progression. Incomplete myotomy may lead to progression of the oesophagus dilating/ further problems, which can be identified by symptoms.

Q2: Has there been any analysis done for predicting which sub-type of Achalasia is more likely to progress to end-stage?

A2: It is not any more likely with different types.

Q3. Is type 1 a progression from type 2 or are some people just affected in such a way that the disease progresses quicker to aperistalsis?

A3: No this is not necessarily the case, but some long term cases would be classified as Type 1.

Treatment centres

Q: I was diagnosed with type 2 achalasia earlier this year. My symptoms are relatively mild but I have been referred to the upper GI team at my local district hospital for further advice.

As this is a relatively rare condition should I ask to be referred to a more specialised unit for further advice re pros and cons of surgery?

A: Sach: Yes it is important to ask what experience the gastroenterologist/ surgeon at your centre has and what treatments they offer or what centres they connect to for more complex treatments. Experience can vary greatly between centres.

Diet Advice

Q1. Is there any general advice that a dietitian can give for those with achalasia, especially children?

A1: It's difficult to give general advice for children as it depends on how much food they can tolerate - but generally keep food soft and moist and take plenty of fluid to get it down. Break up food into small pieces and use lots of sauces and gravies to make it easier to swallow.

Q2. Does it make a lot of difference to their nutritional value if the same fruit and vegetables are liquidised and consumed in the form of a fruit smoothie or soup

A2: The nutritional content is the same but liquidising means that fibre is lost - if constipation becomes a problem then add a fibre supplement to the smoothie.

Soluble v insoluble fibre - this depends on the type of bonds making up carbs - the bonds are stronger in insoluble fibre so help with roughage in poo whilst soluble fibres are easier to digest: this is something to consider i.e. which type of fibre is more suitable for your digestive problems.

Q3. What foods can be eaten to help neutralise the effect of acid reflux?

A3: Catherine: Alkaline diets are absolutely NOT recommended and are not necessary as it's the role of the digestive system, kidneys and liver to balance acidity/ detoxify food. However you can avoid foods that worsen reflux - eg chocolate/ caffeine/ alcohol/ acid fruits/high fat fried foods. Not eating too late before bed. (Majid commented that chocolate causes reflux due to its relaxing effect on the sphincter rather than having acid causing properties per se - therefore achalasia patients shouldn't be affected by chocolate as their sphincter does not relax - some good news, no need to avoid chocolate!

POEM for the under 16s?

Q: One question we would like clarity on is whether POEM has been, or can be carried out on children under the age of 16 in the UK? More specifically could it be carried out on a 15 year old by anyone as a less invasive option to HM procedure?

A: Sach & Majid:

Majid: Would not agree with this as it would leave children open to having reflux for life. It would be better to have a myotomy with a wrap in the first place and to avoid having to have a follow up wrap to deal with the reflux. Endoscopic procedures are not necessarily any less invasive than keyhole surgery.

Alan: He and Amanda met with a specialist nurse Emily White and consultant gastroenterologist Mohamed Mutalib from Evelina Children's Hospital and put this question to him: He said that they try not to do surgery on children if possible as they are still growing. Some cases are referred to them because surgeons are not experienced in performing operations on children with achalasia - there are insufficient numbers for expertise to be built up. He is making a plea to the NHS to develop a centre of excellence for dealing with these surgical procedures for children with achalasia.

Majid: Surgeons do not generally treat children under 16 unless they have undertaken additional paediatric training and have a licence so usually there needs to be a collaboration between a paediatric surgeon and a surgeon specialising in achalasia. Whilst it is advisable to wait until 16 it can be a problem if the child has lots of dilations in the meantime.

Sach: It appears a specialist MDT (multi-disciplinary consulting team forum) is needed as it's not just about surgeons - need to train other professionals in treating children with achalasia - ie gastros/ dietitians etc to make sure all treatment options are considered.

Also need good liaison with adult teams.

End Stage Achalasia

Q: Please could you define "End Stage". Does it always mean removal of oesophagus?

There was a TV News programme last year regarding a liquid medication for Spinal Muscular Atrophy (SMA) disease and Risdiplan medication that had restored their oesophagus and they could swallow again. Is there any chance we could use this??

A: Majid is not aware of any proposals to use Risdiplan for achalasia.

End stage achalasia is when the oesophagus becomes so dilated that it does not function, e.g. food may get trapped in a "u-bend" and unable to move down, meaning that surgical intervention may be required. The need for an oesophagectomy depends on individual circumstances but it is **very rare** for achalasia to end up with an oesophagectomy.

Alan closed the meeting saying that he would like to get back to holding live meetings and Majid confirmed that St John and St Elizabeth Hospital would be happy to host these again.

Donations would be gratefully received from attendees and can be made on the website www.achalasia-action.org/donate-to-achalasia-action.html.