ACHALASIA ACTION

Uniting for a rare swallowing condition

Living With Achalasia

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Introduction

Living with Achalasia is designed to complement our booklet Achalasia Explained, which sets out the symptoms, methods of diagnosis and treatments for the condition. This booklet expands upon this, summarising some of the experiences and helpful tips drawn from people living with achalasia.

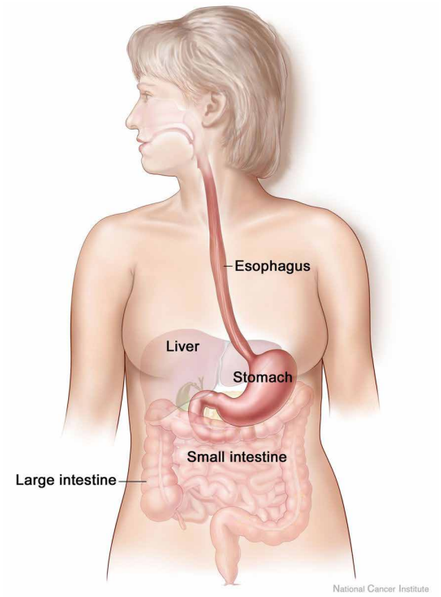
Unfortunately, individual experiences can differ very widely - there is no “one size fits all” for achalasia. So in relation to food, for instance, some have bad experiences with certain kinds of food, but this may not cause problems for others - even some brands of similar food can have a different effect. And problem foods often have an inconsistent effect on an individual - reflux or regurgitation one day may not occur another day.

Experiences can also be very different depending on the stage of the illness - a person recently diagnosed with achalasia, or even someone who has suffered deterioration over some years despite a number of medical interventions, may have different experiences compared to somebody who has had successful treatment.

This booklet seeks to set out the difficulties and navigate the inconsistencies of living with this condition. Following a summary of achalasia as a medical condition, there is information about other topics that may be helpful. This includes food that can cause problems; hints and tips provided by those who have attended our meetings over the years, and other important information.

What is Achalasia?

Achalasia is a rare swallowing condition that prevents the food you swallow from reaching your stomach properly. It affects the muscles in your oesophagus, the food pipe that runs from your throat, down through your chest and to your stomach. (In America and some other parts of the world, the spelling is esophagus). In a normal oesophagus, muscles squeeze the food down towards the stomach by tightening and relaxing in a coordinated sequence in a process called peristalsis. At the lower end of the oesophagus, a valve-like ring of muscle (the lower oesophageal sphincter or LOS) should automatically relax to let food through into your stomach. Then the LOS should close again to stop stomach acid from rising. Peristalsis normally takes two or three seconds and is so effective that some people can drink large quantities of liquid whilst upside down.



With achalasia, the muscles in the oesophagus do not work properly. They are either weak, do not tighten and relax in the right order, or do not work at all. The LOS, located just above your stomach, often fails to open. Food and drink then block back into your oesophagus and can remain there for a long time, sometimes hours or days. This food build-up can create pressure, similar to a blocked hosepipe, until the food either trickles down into your stomach, or is brought back up through your mouth (regurgitation). This is not caused by a fault in the muscles themselves but seems to be a problem with the nerve endings that send signals to the brain to operate those muscles.

Food and Drink that may cause problems

Achalasia interferes with the process of food and fluid passing down the oesophagus and into the stomach. Therefore there may be issues with what you can eat and drink, and this may have an impact on your nutritional well-being.

We have undertaken some limited surveys of people with achalasia. While there are many individual differences and inconsistencies, including the brands of some food causing more problems than others, there are also common experiences that can assist in forming some general guidelines that people may find helpful. So this booklet sets out to help with information so that you can establish your own individual profile of what helps and hinders.

The most likely place for food to get stuck is just above your lower oesophageal sphincter (LOS) which is a sensitive valve that often remains clamped shut with achalasia. This means that relatively small variations in food texture can create a physical blockage, especially if it cannot be chewed into a soft consistency.

Food that may cause obstructions

The most common issue is obstruction of the oesophagus, which may cause discomfort and pain in the chest. The list of foods that can cause problems in this way may not necessarily mean that you have to avoid them completely. It might be that chewing extra carefully or preparing the food differently might avoid the problems for some individuals:

- The skins of grapes, tomatoes, apples, peas etc.
- Salad items or similar fruit and vegetables that may have a difficult texture.
- Fruit or vegetables that are cooked ‘al dente’ rather than soft.
- Stringy runner beans, crisp lettuce and celery.
- Gristle, fat and stringy meat, with red meat more of a problem than white meat which for some people tends to be softer and easier to chew.

- Dry food, such as falafels, raw cauliflower, raw carrot or for some people pizza, which may lack the lubrication provided through sauces.
- Fish containing bones.

Food that may congeal

Certain foods, if retained in the oesophagus for some time, can congeal. Consequently this may create a solid mass that acts as a barrier. Sometimes mixing the textures of food can help the food to pass through into the stomach more easily. Trying just small mouthfuls of this food at any one time may enable you to judge whether there are any adverse effects. Examples of food that can easily congeal are:

- White and processed bread, which is likely to be more of a problem than other breads such as multigrain. Some people find toast better.
- White, fluffy rice, which is likely to be more of a problem than brown rice. Some find mixing with other ingredients and sauce helps.
- Naan bread, as well as some buns and cakes that do not break down easily into digestible form.
- 'Spotted Dick' / suet / dry puddings, or pastry.
- Potatoes and chips. You might try mashing potatoes and mixing it with cheddar cheese and/or sweet potatoes.
- Some people find any kind of pasta causes problems, but may be manageable for some with plenty of sauce.

Irritations

In a normal digestive system, it only takes a few seconds for food to pass through the oesophagus which has a lining that is much more sensitive than the stomach. Delayed transit to the stomach can therefore cause irritation and pain, depending on the nature of what has been swallowed.

- Spicy food can cause irritation if it stays in the oesophagus for a long period. Spice in soups or other food, including pepper, can sometimes cause an immediate reaction in a sensitive oesophagus.
- For some people, even tiny pieces of fruit skin, or seeds from fruit like raspberries can set up a reaction or irritation.
- Alcoholic (and some other) drinks might also cause a similar problem.
- Medications in pill form are often designed on the basis that they will reach the stomach in a normal time before their coating disperses. If they get stuck, their strong chemicals can cause damage to the oesophageal lining. You may request that medication is dispensed in liquid form, if possible.

Temperature of food and drink

Temperature of food and drink affects some people, possibly because very hot or cold liquids set off a reaction from the nerve endings or other sensitive parts of the oesophagus and might trigger spasm pains. For some people, this can even extend to breathing in cold air.

- Hot, or very cold food and drink may cause a problem, probably because of the shock to the oesophagus that this might create. People can experience these heat issues differently from one another, so for one person hot, or cold, water might help; for another it might create a problem. It is sensible to establish what is best for you as an individual.

Diet Guidelines Available

Having to adjust your diet can be difficult, but there are guidelines that may be helpful to give ideas about what to avoid and what might be comfortable to swallow. The International Dysphagia Diet Standardisation Framework (IDDSI) contains advice for people who find food difficult to swallow, or who are at risk of aspirating food into their lungs for a variety of different medical reasons, including the elderly. It also gives examples of food and drink according to levels from **Level 0 - Thin** to **Level 7 -Regular**. It is not specifically designed for people with achalasia, and you do need to appreciate that you may have individual issues with any given food to establish your own pattern of a problem-free diet but **Level 5 - Minced and Moist** may be a good starting point, depending on the severity of your problems. We do emphasise that these are a starting point and you will quite properly adjust them according to experience or further reference to the website link:

https://iddsi.org/Resources/Patient-Handouts

Meat: Serve finely minced or chopped to 4mm lump size, served in thick, non-pouring sauce or gravy.

Fish: Serve finely mashed or chopped to 4mm lump size, served in a thich, non-pouring sauce or gravy.

Fruit and Vegetables: Mash finely or use a blender to chop into 4mm lump size, draining off excess liquid.

Cereal: Serve thick with small soft 4mm lumps. Any milk/fluid should not separate from the cereal. It might benefit from being soaked for a while before being eaten.

Rice: Requires a sauce to moisten it and hold it together. It should not be sticky or gluey and should not separate into individual grains when cooked and served. It may require a thick, smooth non-pouring sauce to moisten it and hold the rice together.

Bread: A warning that it can cause problems.

Useful Hints

Talking to others with achalasia is a good way of getting ideas of what might help with particular problems. Achalasia Action holds regular support meetings, mostly online so accessible to everyone, where people with achalasia get together to help find answers. There are too many ideas to be included here. Check for the details of meetings on the Achalasia Action website.

These hints may need to be adjusted and interpreted according to individual needs, such as severity of symptoms, and whether you have been treated with a surgical procedure:

See the table on pages 8 and 9.

Meals	Eat smaller meals on a more frequent basis – 'little and often' is usually best. It may be better to tolerate 4-5 smaller meals spread across the day, rather than attempting three larger meals.
	Eat slowly and chew well. Chew each mouthful of food for at least 10-15 times. Digestion begins in the mouth.
	Eat slowly and give time between mouthfuls, waiting until the previous one has cleared into the stomach. Otherwise swallowing again will simply build up pressure of undigested food and stretch the delicate oesophagus.
	Do not eat late in the evening. When in bed, gravity will not be able to help the food to go down into the stomach and it might flow up to the throat.
	Sit at a table while eating, and try to maintain an upright posture - even standing up if necessary.
	Beware of eating when in a hurry or when feeling stressed.
	Eat food that is moistened, for example with sauce or gravy or with accompanying sips of water.
	Be aware of your own digestive capacity. Try not to reduce the chance of coping with a main course by eating too many nibbles beforehand. If, however, you need to graze during the day to sustain your calorie intake, try to make what you eat as healthy as possible.
	Be familiar with the types of food that you personally find difficult to cope with. It may be helpful to keep a food diary which tracks food eaten against possible symptoms. Remember that you might have residual food in your oesophagus which causes problems for subsequent meals, so look at the whole picture.
	Sometimes mixing food of different textures can help to avoid food sticking together. For example, try eating custard with a sponge cake, or chicken with lots of gravy. Multi seeded bread, preferably toasted, seems to work better than white bread.

	Tender, young vegetables can be easier to eat than older tougher ones.
Reducing food blockages	Some have reported that sparkling water or a carbonated drink may be helpful in reducing the food blockages. Drinks like Pepsi Cola and other soda or carbonated drinks do seem to help with food blockages because of their chemical action. They can be used in other medical situations to clear feeding tubes, for instance.
Drinking	Drinking, perhaps hot or cold water, with meals can help to lubricate food and make it easier to pass through into the stomach, but be careful if the oesophagus is completely blocked; drinking more liquid might simply increase the pressure.
Temporary relief from food blockage discomfort	Try lifting the chest, stretching upwards, elongating the neck and taking deep breaths.
	Getting up and walking around during mealtimes can encourage gravity to help food to pass through into the stomach.
	Massaging the chest area.
	Jumping, or standing on toes and dropping on to heels can sometimes dislodge stuck food.
Toothpaste	Be careful to avoid swallowing toothpaste or mouthwash.
Bedtime	Sleeping with head and shoulders raised can help prevent reflux or undigested food flowing towards the throat. Use pillows, a bed wedge, rolled blankets underneath the head of the mattress, prop up the feet of the bed, or even consider an adjustable bed.
	Lying on your left side may be better at dealing with the risk of reflux because the oesophagus is connected to the right side of the stomach. This means that lying on your left may help the acid from being pushed back up into the oesophagus.
	It can be helpful to try, if this is realistic, to ensure that the oesophagus is as clear as possible overnight.

Nutritional Implications: Diet and Achalasia

While some patients with achalasia may lose weight because of impaired swallowing, other patients do not. Research explaining why this may be the case is unfortunately lacking. Consequently there are no formal evidence-based guidelines on diet and nutrition for people with achalasia.

Check carefully about any source of nutritional advice, as this can be given by people without medical qualifications, who may not operate under a code of ethics and who may often have something to sell.

There is 'no one size fits all' approach to diet and achalasia. The lived experience can be very different for each and every person with the condition.

Whilst it is generally important to maintain a healthy, balanced diet, the sheer difficulty, for some, of swallowing anything might mean that the details of nutritional value might have to take a lower priority in the short term.

The most serious cases of achalasia may result in malnutrition and weight loss, which impacts on nutritional well-being. You may need to ask your doctor to refer you for nutrition support with a dietitian.

General advice on diet

We cannot provide detailed, individually-tailored dietary advice in a booklet like this. That said, if you would like support with your eating and drinking, you can ask your GP about making a referral to a community dietitian. If you are under the care of a hospital consultant, you can ask for a referral to a hospital dietitian. Meanwhile, some general advice includes:

- Keeping a food diary that tracks food eaten against symptoms. It is possible to find out by 'trial and error' what works, or does not work.

- A blender or liquidiser is very useful. Blending vegetables and fruits may make them easier to digest.
- Adding olive oil and/or butter to vegetables and potatoes will add additional calories if you are concerned about weight loss.
- Meat can be braised or slow-cooked to make it softer and easier to digest.

Vitamin Supplements

- Vitamin supplements are normally only necessary if a valid blood screening test from a medical professional has shown a specific deficiency, so if you suspect that you may be low in vitamins or minerals because of achalasia, ask your GP for a test.
- The one exception is vitamin D. Vitamin D is really important for bone, tooth and muscle health. From October to early March everyone in the UK is advised to take a daily vitamin D supplement. Children over 4 and adults are advised to take a 10 microgram (400 IU) during the autumn and winter.
- People at risk of vitamin D deficiency are advised to take a daily vitamin D supplement throughout the year. This includes:
    1. People who are not often outdoors – for example, if they're frail or housebound, or live in an institution such as a care home.
    2. People who usually wear clothes that cover up most of their skin when outdoors.
    3. People who have dark skin.
    4. People with medical conditions which increase vitamin D deficiency.

The NHS guidance on vitamins can be found online:

https://www.nhs.uk/conditions/vitamins-and-minerals/

Vegans

If you are vegan, the same priority about taking food that you can swallow still applies, but the Vegan Society has helpful information including the vegan eatwell guide:

The Vegan Eatwell Guide (vegansociety.com)

Cholesterol

If you are concerned about your cholesterol levels, perhaps because you are eating certain types of food to avoid losing weight with a diet restricted by achalasia, there is some general advice that you might find helpful available from the British Dietetic Association:

https://www.bda.uk.com/resource/cholesterol.html

The British Heart Foundation also has some helpful information about reducing cholesterol:

www.bhf.org.uk/informationsupport/risk-factors/high-cholesterol/five-top-questions-about-lowering-cholesterol

Websites

Websites for evidence - based advice on nutrition and well-being:

- Dr Hazel Wallace, The Food Medic:
  https://thefoodmedic.co.uk
- Maeve Hanan – Dietetically Speaking:
  https://dieteticallyspeaking.com
- Research dietitian Dr Megan Rossi, The Gut Health Doctor, an education hub with lots of useful resources:
  https://www.theguthealthdoctor.com

Books you may find useful to read:

- **The Diet Myth**, Professor Tim Spector
- **Food Isn't Medicine**, Dr Joshua Wolrich
- **Eat More, Live Well**, Dr Megan Rossi

Pain and Spasms

Pain issues in general

Many people with achalasia have episodes of moderate to extreme pain in their chest area. Sometimes this pain can be caused by nerve/muscle spasms, sometimes by reflux, sometimes by food being stuck. It is not always clear what causes the pain. It varies between individuals, including how, where and whether we feel it. Pain with achalasia is a particular problem as it is often unpredictable and sometimes occurs without an obvious trigger. It is difficult to explain, difficult to treat and difficult to live with. There is a great range of experience with achalasia.

The body can become used to tolerating pain. People may find that their symptoms change over time; sometimes, for instance, variations in pain occur when the oesophagus becomes dilated.

The sensations can be extreme chest pains that shoot to the back or jaw; they can occur at any time of day but especially at night. People report that the pain is sometimes dull in the background and sometimes sharp and quite intense. Descriptions have included "**like a heart attack**", "**like I've swallowed glass**" or "**similar to the sensation of cramping hamstring pain transferred to the chest**". It is always important for the pain to be defined and investigated to establish whether it is related to achalasia or not. It is important to rule out causes like a heart attack. Having achalasia does not exclude also having other medical conditions!

Pain occurs because the oesophagus is trying to protect itself and sends signals to try and stop the cause of the irritation. Secondary pain can then occur, which causes an increase in sensitivity after, say, a couple of days of problems. Pain signals are passed through the nerves to the spinal cord and up to the brain which then interprets what is happening in the body. If these pain signals are repeated constantly, the nerves in the spinal cord themselves then become more sensitive and this creates ever stronger pain signals that are passed to the brain.

Pain can be transferred (or 'referred') to other parts of the body because of innervation – the way that nerves inter-connect. Investigation of pain has to take into account that the location of the cause of the pain may be quite different from where the sensations are felt.

When pain signals reach the brain they integrate with emotions. They affect how you feel and can rouse anxieties and memories of previous pain.

Some people report chest pain as their first symptom before they are diagnosed with achalasia and sometimes even before they experience problems with swallowing food and drink. Chest pains from the oesophagus can be quite panic-inducing and so severe that when first experienced they can be mistaken for a heart attack.

The oesophagus itself does not have many nerves as such, but the spasms can continue to build up progressively and transmit pain to other parts of the body through the parts of the nerve system in the spinal cord that travel to the heart, arm or jaw and then to the autonomic nerve system that affects sweating, clamminess and palpitations. The effect can be ischaemic (affecting blood supply) and the muscles can then start to run out of oxygen, making things worse.

Irritation

Pain felt in the gullet (oesophagus) is often linked to irritation eg by hot or acidic foods, or by food getting stuck. The oesophagus naturally wants to empty itself, so irritation can occur when food remains in the oesophagus rather than being cleared through into the stomach. Saliva normally washes this food residue through to the stomach, and when saliva also gets stuck, this process does not work properly and the irritation gets worse. Spasms can be a reflection of the nerve system dilating the oesophagus and trying to get rid of residual food (as if it is an angry oesophagus).

Irritation can also be caused by acid reflux from the stomach, especially at night when you are horizontal. Reflux can then flow more easily 'upwards' into the oesophagus. Reflux can create the pain known as 'heartburn' when stomach contents create a reaction from the lining of the oesophagus which is not, unlike the stomach, designed to withstand strong acid.

Sometimes the Upper Esophageal Sphincter (UES, the valve at the top of your oesophagus that prevents food and drink from entering your lungs) does not relax well, and this can trap gas within the oesophagus. Normally this will be burped out, but trapped gas can also be a cause of pain.

Fermentation of residual food in the gullet can also be a contributory factor to irritation.

Causes and triggers

- If spasms are associated with meal times, the cause might relate to food becoming stuck.
- At other times, food remaining in the oesophagus may cause irritation leading to spasms.
- The lower oesophageal sphincter is often clamped tight shut, causing pain to radiate outwards, leading to shortness of breath, a clutching/squeezing sensation and/or losing one's breath.
- If spasms and chest pain are experienced at night, it may be more likely to be related to reflux because of being horizontal.
- There can be deterioration of the normally well-balanced nerve receptor (excitatory and inhibitory) activity controlling the muscles for effective swallowing (peristalsis) that translates into pain.
- The vagus nerve system that controls much of the digestive process can develop involuntary movements and reactions.
- Stress is the most commonly reported trigger and will exacerbate symptoms even if it is not the primary cause.
- Environmental factors such as cold air, humidity or changing weather can be relevant.
- Some have reported triggers such as sneezing, coughing, bending or other sudden movements.
- Fatigue or illness can often make things worse.
- Food or drink that is too hot, too cold or too spicy can cause problems.

Treatment for spasms

Because of this range of experience, medical treatment will depend on establishing the cause of the spasms and pain.

Over time, people with achalasia often find solutions to help avoid painful muscle spasms, which are not caused by reflux, especially if they carry out the techniques that work for them, as soon as they feel a spasm starting. This can include holding a hot water bottle or warm pad on your chest, drinking warm water and relaxing breathing techniques. Taking notice of triggers for spasm pain is also important. This can include breathing in cold air (wearing a mask can help) or stuck food, or even an empty oesophagus. Just a sip of warm water can make a big difference. Everyone is different though, so it can be trial and error to find out what works for you. Relaxation is important.

Checks can be made for reflux. Even small amounts of reflux can create a reaction. Proton Pump Inhibitor medication such as Omeprazole (see under Medication) can reduce the amount of acid created within the stomach. In some cases it may be appropriate to undergo 24-hour pH monitoring to investigate acid reflux. Sleeping with your head raised by means of extra or special pillows, raising the head of your bed, and avoiding eating late in the evening can be helpful to stop reflux creeping towards your throat when you are horizontal. Lying on your left side in bed may also help as the oesophagus joins the stomach on its right side.

Doctors will check for any obstruction in the oesophagus to judge whether an intervention such as dilatation or a myotomy might relieve the condition so as to allow food to pass through into the stomach by gravity.

If the oesophagus is subject to vigorous, uncoordinated muscle contractions, these may cause an obstruction as well as pain.
Doctors may prescribe medication to try and relax the oesophagus (eg Nifedipine, angina remedies, sublingual GTN).
External stress is frequently a factor. It can have a direct effect on stomach emptying as it acts as an accelerator on the digestive system and makes it more chaotic. Past experience of pain can be exacerbated by stress. Using relaxation techniques can help. Psychotherapy and/or cognitive behaviour therapy can be considered.

Prevention

- Lifestyle changes may prevent spasms eg modify diet to exclude known triggers, avoid stress and use relaxation or meditation techniques.
- Exercise can help - being fitter and stronger in one's core can help with coping with pain.
- Resistance training, properly supervised has a lot of metabolic benefits (two x half hour sessions per week).
- Yoga and Pilates can also be helpful.
- Improving diet can help, especially being careful about the texture of food, e.g. things that could clog the system such as bread, rice, fibrous meat, vegetable skins.
- Eat more slowly, chewing food thoroughly.
- Drink water with food to help it go down. The temperature of the water needed to help the food go down will vary from person to person - some need it to be hot, and others very cold, as well as other temperatures in between. Experiment to find out what works for you.

Research into pain and spasms

Treatment of achalasia is often focused on improving the movement of food through the digestive system, with the management of pain as less of a priority. There has not been much research on medication that might help. It is difficult to analyse random spasms without a pattern if doctors cannot examine the patient when the spasms are actually occurring. Some studies have apparently found that Sildenafil (Viagra) can sometimes help spasms because of its effect on improving blood flow.

In one study (Patti et al, 2008) involving 167 myotomies, 55% had pain beforehand, and 95% improved afterwards. An Achalasia Action survey of 57 people with achalasia in 2017 found that 70% had experienced spasms.

Medication

People with achalasia may need to take medication for other reasons, and if so may need to take extra care because pills may simply remain in your oesophagus rather than reaching your stomach and then being absorbed into your body through your digestive system. The chemicals from the pills might damage your oesophagus which is different in nature from your stomach lining.

- Many medications can be given in liquid or powder form. Your pharmacist can advise you about this, and your doctor might need to specify this on the prescription.
- If you need to take medication in tablet or capsule form, take them, subject to the medication information leaflet, before meals with plenty of water to improve the chances of them passing into your stomach.

Some people do not need to take medication related to achalasia, but information is included below about some associated medication that is not directly aimed at achalasia itself, but may be given to reduce the symptoms in various ways, eg to reduce reflux, or to relax certain groups of muscles to combat spasms.

For severe cases of pain, you should beware of liquid opiates because of the addiction and constipation issues, and should seek specialist intervention to diagnose the cause of the pain.

As always, you should seek medical advice before taking medication.

Proton pump inhibitors (PPIs)

The most common medication taken by people with achalasia are proton pump inhibitors (PPIs) that switch off the production of stomach acid. Names of common PPIs include Omeprazole, Esomeprazole, Lansoprazole and Nexium. These are widely used, safe medications, typically taken half an hour before eating (but there is a need to check the label for this). PPIs may be essential for those who suffer from long term reflux. Reflux occurs when stomach contents seep into the oesophagus from the stomach past the lower oesophageal sphincter (LOS) which should normally act as a valve to prevent this. Achalasia often means that the LOS does not relax, so procedures to improve achalasia can result in the LOS being loosened with the risk that reflux can be increased, particularly when lying down at night. A fundoplication, which wraps part of the top of the stomach around the base of the oesophagus with a Heller's myotomy, is designed to re-create a valve effect to prevent reflux, but some degree of reflux is still possible after this and other interventions.

As with all medications, side effects may occur. The normal state of the stomach is acidic and we need this gastric acid to help digest our food and absorb vitamins and minerals. The normal level of acidity also allows us to maintain a healthy balance of our own natural gut bacterial flora downstream. In the case of PPIs, the reduction of acid may also reduce the benefits of that acid to promote good digestion and normal gut bacterial flora. Absorption of Vitamins B12 and C, and calcium, iron and magnesium may be affected. PPIs also have some other side effects too, especially if taken longer term. This emphasises the importance of periodic reviews to make sure that you still need to take PPIs.

PPIs only work against acid, and will not be effective against bile reflux (alkali). Stopping PPIs can create a 'bounce' effect of experiencing more reflux for some days until your system re-adjusts.

www.nhs.uk/medicines/omeprazole

Other reflux remedies

There are medications such as H2-receptor antagonists (eg Zantac) and antacids (eg Rennies, Tums), that also combat stomach acid. Gaviscon Advance is an inert alginate medication that creates a temporary protective raft to defend against both acid and bile reflux generally and can be effective for occasional reflux symptoms. Sucralfate (also known as Carafate) works in a similar way, but is available only on prescription.

www.nhs.uk/medicines/gaviscon

Peppermint Oil

Peppermint oil is an antispasmodic medication that helps to relax muscles in the wall of the bowel (brand names Apercap, Colomint, Colpermin, Mintec) and can be bought over-the-counter.

www.nhs.uk/medicines/peppermint-oil

Buscopan

Buscopan is an over-the-counter remedy that can combat spasms in the gastro-intestinal tract.

www.nhs.uk/medicines/buscopan-hyoscine-butylbromide/

Nitrates

Nitrate medications, such as Glyceryl Trinitrate (GTN, brand names: Rectogesic, Minitran), are designed to increase blood flow. They can relieve chest pain and can be helpful, especially against painful spasms. GTN sprays may be useful when it is difficult to swallow.

www.nhs.uk/medicines/glyceryl-trinitrate-gtn/

Calcium Channel Blockers

Calcium Channel Blockers (e.g. Nifedipine) are used to lower blood pressure by reducing the amount of calcium entering the heart and arteries and allowing blood vessels to relax and open. They can also be used for some other conditions like angina.

www.nhs.uk/medicines/nifedipine

Sildenafil

Sildenafil commonly known as Viagra is not licensed for dealing with spasms and very few specialists prescribe it, but it is a powerful smooth muscle relaxant (ie for muscles in hollow digestive system organs) that can be used as a last resort.

Diazepam

Diazepam belongs to a group of medicines known as benzodiazepines and is used to treat anxiety and muscle spasms. It can be applied with a tube through the anus, and can be used in extreme cases of spasm pain.

Medical cannabis (CBD)

There is some anecdotal evidence about medical cannabis having muscle relaxing properties. Current evidence is not convincing, however, but it might be a development for the future.

Some of the above prescriptions may need to originate from a specialist, but may then be continued by a GP.

Thrush (Candidiasis)

Thrush is an infection caused by a yeast (a type of fungus) called Candida. The condition is also known as Candidiasis and is normally apparent because of white growth deposits. It can appear in the mouth, throat and oesophagus. Oesophageal candidiasis can lead to difficulty and pain when swallowing, but is sometimes difficult to detect in the oesophagus without an endoscopy and sometimes occurs without the person being aware of it.

Candida normally lives on the skin and inside some parts of the body without causing a problem, but it can grow and multiply if the environment changes in a way that encourages fungal growth. Having a dry mouth because of interruption to the normal flow of saliva can be a factor for thrush, as can a poor immune system or lack of iron, vitamin B12 or folic acid.

It can normally be cleared up with anti-fungal medication for which you should see your doctor.

Mapping the Experiences of People with Achalasia

Melika Kalantari MPharm(Hons) MSc from the University of Reading has conducted some original research amongst members of Achalasia Action that was published in November 2020.

(https://onlinelibrary.wiley.com/doi/10.1111/hex.13160)

She points out that the onset of achalasia symptoms can typically be insidious over a number of years, that there are often delays in diagnosis and that behavioural and lifestyle adjustments are required for this chronic condition. Three quotations from the published paper give a flavour of this research:

'According to a study carried out by Clark et al, three separate categories of activities need to be addressed in order to successfully self-manage a chronic condition. First, people with chronic conditions need to have an adequate knowledge about their condition and its treatment to make informed decisions. Second, they need to perform activities in order to manage their condition by making changes to their lifestyle, including changing their dietary habits. Third, they need to apply skills to maintain adequate psychosocial functioning, which includes working, maintaining a good family life and cultivating social relationships. These self-management activities aim to reduce the impact of chronic conditions on daily life.'

'There is no one way to manage the symptoms of achalasia; therefore, people living with this condition need to manage their symptoms by trying different self-management strategies through trial and error.'

'The study highlighted the issues people faced at each stage in their journey and identified the areas that need addressing to help people cope with their condition, including interventions to improve patient care. The process map also highlighted the importance of self-management of chronic conditions. People who participated in this study may have undergone different medical treatments, but all of them were still experiencing symptoms that required them to adopt different self-management strategies to carry out their normal lives.'

Relaxation, Complementary Therapies and Stress Management

Stress and tension can have an adverse effect on making swallowing more difficult for people with achalasia, and this can apply both before and after medical treatment for the condition. Coping with achalasia can also be a challenge from a mental health perspective. Sometimes there is little evidence in the form of medical trials on which recommendations can be based in relation to different approaches and techniques, but on the basis that some people have found them helpful, it can be justified to give them a try carefully if you feel drawn towards a particular approach, but not to hesitate to withdraw from the treatment after a few sessions if you feel that no benefit is being achieved.

Some complementary therapists have voluntary registers (some of which are accredited by the Professional Standards Authority for Health and Social Care, or the PSA) or professional associations that practitioners can join if they choose.
Some of the approaches are listed below but do not amount to a recommendation for any individual, or generally. They are intended merely to give more information and to signpost where more detail is available.

Acupuncture and Acupressure

Acupuncture originated from ancient Chinese medicine and involves fine needles being inserted at certain points in the body for therapeutic or preventive purposes. It is sometimes used in some NHS GP practices, in pain clinics and in hospices in the UK, but clinicians may be unwilling to refer people for acupuncture on the basis of insufficient data from medical trials. One experiment with medical students established that pain in the oesophagus was reduced when the person's foot was plunged into cold water, thereby indicating that a beneficial effect could be achieved through the nervous system. Acupressure involves pressure being applied to certain points of the body rather than needles being inserted.

www.nhs.uk/conditions/acupuncture/

Hypnotherapy

Hypnotherapy is not available on the NHS but can be used to treat some conditions or to change habits. The therapist will discuss what methods will be used and may lead you into a deep, relaxed state, after which most people feel relaxed and refreshed. In the UK, there is no law to oblige hypnotherapists to have specific training. The NHS website advises that people should seek a hypnotherapist who has a medical background.

www.nhs.uk/conditions/hypnotherapy/

Reflexology

Reflexology is used by some people who find it generally relaxing and helpful to alleviate stress. The theory is that pressure applied to areas of the feet correspond to certain organs and systems of the body. Foot charts are used so that pressure is applied to certain parts of the feet. It is sometimes combined with other hands-on therapies and may be offered by chiropractors and physical therapists, among others.

Research evidence about reflexology is sparse. It is not widely available on the NHS but is sometimes used to help cancer patients, for instance, relax.

Mindfulness

Some people are attracted to mindfulness on the basis that being more aware of our surroundings helps our mental well-being and may help to deal with stress and anxiety. The NHS website describes mindfulness in more detail.

https://www.nhs.uk/mental-health/self-help/tips-and-support/mindfulness/

Yoga

Yoga concentrates on strength, flexibility and breathing to boost physical and mental health, and it is said that there is some evidence that it can help people with stress, depression, high blood pressure and aches and pains.

www.nhs.uk/conditions/nhs-fitness-studio/yoga-with-lj/

Tai Chi

Tai Chi, also known as Tai Chi Chuan, combines deep breathing and flowing movements. It originated as a martial art in China, but is now appreciated around the world as a health-promotion activity.

www.nhs.uk/live-well/exercise/guide-to-tai-chi/

Further Reading

Achalasia Action places records of meetings and discussions on a number of relevant topics on our website:

https://www.achalasia-action.org/information-hub.html

Reading medical journals can be a daunting prospect, and one should not place too much significance on findings where only a small number of patients are included in the research. They are written for people who are medically qualified and able to make discerning judgements.

While some examples are shown below, there will almost certainly be important articles elsewhere. The best course in cases of doubt is to seek advice from the doctor who is dealing with your condition who can put things in proper context for your own situation.

Minimally Invasive Surgery for Achalasia: An 8-year experience with 168 Patients Marco G Patti, Carlos A Pelligrini and others Ann Surg. 1999 Oct; 230(4): 587

http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1420907/

Achalasia: A Systematic Review John E Pandolfino and Andrew Gawron JAMA 2015; 313(18):1841-1852 doi:101.100.1001/jama.2015.2996

www.ncbi.nlm.nih.gov/pubmed/25965233

Is it an Eating Disorder, or Achalasia, or Both? A Literature Review and Diagnostic Challenges Deborah L Reas and others. Published online 22 July 2014 in Wiley Online Library DOI: 10.1002/erv.2307

http://www.ncbi.nlm.nih.gov/pubmed/25053457

Diagnosis and Management of Achalasia Michael F Vaezi and Joel E Richter American Journal of Gastroenterology Vol 94 No 12 1999.

http://s3.gi.org/physicians/guidelines/DiagnosisofAchalasia.pdf

European guidelines on achalasia: United European Gastroenterology and European Society of Neurogastroenterology and Motility recommendations RAB Oude Nijhuis et al.

https://doi.org/10.1177/2050640620903213

Notes

Notes

If you would like to receive newsletters and/or help us to raise awareness of achalasia, publish helpful information, organise patient support meetings, run our helpline, or contribute to research, please complete this form and send it to Achalasia Action, 40 Orpington Road, London N21 3PG.

I would like to receive periodic information from Achalasia Action Yes ◯ No ◯

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ACHALASIA ACTION

Uniting for a rare swallowing condition

About Achalasia Action

In January 2020, Achalasia Action was registered as a Charitable Incorporated Organisation by the Charity Commission of England & Wales (no 1187367)

The charity's aims include:

- To advance education about achalasia and associated conditions.
- To preserve and protect the health of people with achalasia,
- including their friends and families.
- To encourage and support research into achalasia

To find out more about our support group meetings, to sign up for our newsletters, or to discuss your situation please visit **www.achalasia-action.org** or use our helpline

0300 772 7795

To make a donation to our charity, please visit **www.achalasia-action.org/donate-to-achalasia-action.html** or complete the page inside and send it to us by post.

Scan Me

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