When any patient, following diagnostic tests, is told by their colorectal surgeon that an operation resulting in the formation of a stoma is necessary they will naturally feel very apprehensive and frightened. Whilst stomas have been formed surgically for many years, most patients confronted with this prognosis can only think back, perhaps to their relatives who might have had a colostomy many years ago and assume that their fate will be similar with the attendant inconvenience and odour. Fortunately, research and development within the stoma field has progressed enormously over the last few years, pouches of all shapes sizes and applications are available and most people can, after a period of convalescence, return to a perfectly normal life. However, part of this transition will be a steep learning curve with the help and support of your stoma nurses but the internet has provided patients with the opportunity to research the situation for themselves.

It is therefore vital that literature is available to help in this readjustment process and the booklet that you are about to read will, I am sure, be of enormous help to you but, coupled with this is the opportunity to discuss any fears or worries which you might have with people who have already undergone the procedure and this is where The Colostomy Association can help you by using our twenty-four hour helpline manned by colostomists.

The freephone helpline number is 0800 328 4257, you can visit the web site at www.colostomyassociation.org.uk or email cass@colostomyassociation.org.uk. Please contact us if you are the slightest bit worried, our volunteers know what you are facing and can help you through your recovery.

Monty Taylor
Chairman of Trustees
The Colostomy Association
2 London Court, East Street
Reading RG1 4QL
Introduction

It is a worrying time when you learn that you need to undergo major surgery. It can be particularly traumatic when you learn that as a result of that surgery your bodily functions will not be the same – that you will have a ‘colostomy’ and will not be able to pass motions in the normal way but will wear a ‘pouch’ on your abdomen.

You may not have heard of a colostomy or a stoma before or have only a vague idea what one is. You may feel horrified and upset, or temporarily numb at the news. Whatever your reactions and feelings, you will find hospital staff very understanding and supportive. They have helped very many people through the same experience and back to a full, active and happy life.

Very experienced nurses who specialise in stoma care will be there to care for you and help you with information, practical assistance, advice and reassurance about what having a stoma involves. A support organisation like the Colostomy Association can help with advice and visits from other (happy, healthy) colostomists. The creation of a stoma is often a lifesaving operation, and for many people – there are thousands and thousands of people with colostomies – it actually improves the quality of their lives.

By the time you leave hospital you will be able to manage the pouches for your colostomy. You will in your own way learn to cope and to come to terms with the change in your body and with your stoma. Caring support is also readily available within the community, so you won’t feel alone. Soon, your stoma seems less important, and becomes just an everyday part of your life.

This booklet is intended to ‘fill in’ on some of the information you may have been unable to take in at the time of your surgery, to give you background information and practical advice about the day-to-day care of a stoma and to answer some of the queries that are bound to arise. It will also act as a reference source of other relevant organisations and of advice available.

How the digestive system normally works

Digestion begins in the mouth where the food is chewed. Swallowed food passes down the oesophagus ① into the stomach.

The stomach acts like a liquidiser, churning the food in digestive juices until it is reasonably liquid and passing it into the ileum ② or small intestine.

The food passes along the small intestine (the walls of the stomach and intestines contain muscles that expand and contract to produce a wave like movement that urges the food onwards – this is called peristalsis).

During its journey through the small intestine most of the nutrients in the food are absorbed into the body, leaving a fairly liquid mixture of indigestible matter and water.

The large intestine, or colon ③, has the job of taking water back into the body, leaving the indigestible or waste matter (faeces) in a semi-solid form.

At the end of the colon, waste material is stored in the rectum ④, before being expelled through the anus ⑤.
What is a colostomy?

There are three types of stoma procedures: colostomy, ileostomy and urostomy.

Sometimes part of the rectum and/or colon has to be removed or temporarily bypassed. This means that faeces can no longer leave the body via the anus in the usual way.

The surgeon therefore needs to create a new outlet for faeces to be passed and this is done by making an opening onto the abdomen at the front of the body. This opening is called a colostomy.

A colostomy may be sited at one of several places in the colon – usually on the left hand side.

A small opening is made on the outside of the abdomen and the end of the remaining colon is brought through and attached to the surface. This is a stoma. (The words ostomy and stoma come from the Greek word meaning ‘mouth’ or ‘opening’ and a colostomy is an opening created in the colon.)

A stoma looks like a small spout, deep pink in colour similar to the inside of the mouth. Although it looks raw, it has no feeling. Waste matter (faeces) comes out of the stoma and is collected in a special stoma pouch attached around it.

Mucous fistula

Sometimes, if the rectum has not been removed but is left in place, the cut end of that may also be brought to the surface to make a small opening called a mucous fistula. This usually needs little attention.

The waste matter from a colostomy

Food from the stomach travels round the small intestine, where nutrients are absorbed leaving just indigestible matter and water. This then travels round the part of the colon that remains and is passed out of the stoma. At first there is little control over this but often a regular pattern will emerge.

The colon has the job of absorbing water from the waste matter back into the body. The consistency of the waste material passed will therefore depend on how much colon is left – the further along the colon the stoma is situated, the more water will have been absorbed and the firmer the faeces will be.
Why are colostomies carried out?

Like any other major surgery a colostomy is not undertaken lightly and doctors will only recommend it where absolutely necessary.

**Permanent colostomy**

There are many reasons why surgery may have to be carried out and a permanent colostomy created. These include obstructions or growths of some kind in the colon or rectum, accidental injury, and occasionally severe cases of inflammatory bowel diseases like Crohn’s disease.

Sometimes, patients will have had little idea that anything was seriously wrong because their condition caused only minor symptoms. The proposed surgery can therefore come as a shock, but it is necessary before further problems develop. For others, surgery can bring welcome relief from years of bowel problems. A colostomy in itself will not stop anyone from leading a full and active life.

**Temporary colostomy**

Colostomies can also be created as a temporary measure, to allow part of the intestine to rest and heal. Rejoining of the intestine then takes place at a later date.

A temporary colostomy may be created following accidental injury, or as part of the treatment for severe diverticular disease, where small pockets of faeces become trapped in the bowel and cause inflammation, pain and bleeding, or for some other reason where the gut needs to be bypassed for a while.

The surgeon will advise if the colostomy is just a temporary measure. Day-to-day care of the stoma, however, remains the same.

Before your operation

**Before your operation**

Members of the medical team will help to prepare you and advise you about your coming operation and answer queries. The procedure will be carefully explained to you and the doctor will tell you whether your colostomy is going to be a permanent one or if it is being created as a temporary measure.

It is quite likely that you will not be able to take in all the information at first. It may help to jot down any queries you have as you think of them, so that you can remember what to ask.

In many hospitals specially trained stoma care nurses will be available to help you and your family. These nurses will be closely involved in your care and will make sure you have continued support in the hospital and at home. It may be helpful to meet another person who has experienced living with a colostomy and this can be arranged, usually through the Colostomy Association.

Before you come into hospital for your operation, you may be given a chance to practice changing a pouch. This can help you to become confident more quickly at looking after your stoma after your operation.

**Where will the stoma be?**

A colostomy is often sited on the left side of the abdomen but it depends chiefly in which part of the colon the colostomy has been created. Usually a mark is made on your abdomen before the operation. You can become involved in this planning by indicating what might suit you best, by sitting and standing and discussing what clothes you like to wear, and where the waistbands are likely to come.

You should also make sure you can see where the stoma will be, to make appliance changes easier.

Before the operation you will probably have your bowels emptied and a washout given – medical staff will advise.
After your operation
When you first come round you will find there are various tubes attached to you and you may feel some weakness or discomfort. This is quite normal after any operation. All the tubes and drains will gradually be removed during the following days, you will feel stronger and you will start to drink and eat.

Your stoma will begin to be active within a few days. You will be encouraged to help with looking after your colostomy as soon as possible. At first the stoma will be swollen, surrounded by stitches, and the pouches used at this stage are transparent and may be slightly cumbersome. The swelling will soon begin to go down, however, and the stitches disappear by themselves or will be removed. The stoma will become smaller and neater. (The stoma will continue to become smaller even after you are allowed home and you will need to check that your pouches are still a good fit.)

Leaving hospital
When you leave hospital you will be given full details of how to contact your stoma care nurse for information or advice. You will also have an appointment for your first check-up at the hospital and your family doctor will be notified of your return home. You will be given enough supplies of pouches to keep you going for the time being plus a detailed list of the items you use so that you can ask your doctor for a prescription.

You are likely to be in hospital for somewhere between five to ten days. The stoma care nurse will teach you how to change pouches, how to measure the stoma to see that the aperture of the stoma pouch is correct and how to care for your stoma generally. Your stoma care nurse will also fit you with a more discreet type of pouch, after discussing with you what types of pouch are available.

Blue disposal bags and wipes are supplied free to patients ordering supplies through the SecuriCare Home Delivery Service. For information call free on 0800 585125.
When you return home

Support is available from your stoma care nurse and/or community nurse. The stoma care nurse can be contacted by phone, and many hold regular stoma clinics. The Colostomy Association and other support groups are very helpful and supportive.

Ask your doctor to give you a prescription for the stoma care items you need. You are exempt from charges if you are over 60. People of any age are exempt from charges if their colostomy is permanent. Apply for exemption on the special FP92A form given to you in hospital or available from your doctor or local Department of Health office*. The form should be signed by your hospital doctor or GP.

How to obtain stoma care supplies

Your doctor writes you a prescription. You can then go to your local retail chemist in the normal way. They may need a little time to obtain the items you need, so do not wait until supplies are too low.

Supplies may also be obtained direct from the manufacturers of the pouches you use, and also from general ostomy suppliers. You will need to send your prescription to these organisations. Manufacturers are also very helpful if you need emergency supplies.

If you would like information about the wide range of stoma care pouches and accessories please contact the Careline on Freephone 0800 585 125

www.securicaremedical.co.uk

Your stoma care nurse will be able to show you a selection of pouches and accessories available and will advise you on their use.

To help you when choosing a pouch that is right for you call the SecuriCare Careline 0800 585125.

Colostomy pouches

The waste passed out from a colostomy is usually fairly firm so a ‘closed’ or non-drainable stoma pouch is used. The pouch is removed and replaced with a new one once or twice a day, or as required.

The consistency of waste matter passed out of a stoma does vary, however, according to the position of the colostomy in the colon. If the waste is very liquid (and therefore in greater quantities), some colostomists wear drainable stoma pouches clamped shut at the bottom. The pouch can be unclamped and emptied as often as necessary during the day.

Whether you wear a closed or a drainable pouch, you will find there are basically two types of stoma pouch, one-piece and two-piece.

One-piece pouches

These simple pouches are very popular and easy to manage. They are fixed around the stoma by means of a skin friendly hydrocolloid, self-adhesive wafer.

When changing a pouch for a fresh one, the whole pouch is gently removed and a new one applied in its place.

* Applies to England only.
Stoma pouches

The type of self adhesive wafer and precise means of attaching the pouch vary with different types and makes, so it is worth experimenting to find one that suits you, your skin and your way of life. All of the Welland pouches, for example, are affixed with HyperFlex®. HyperFlex is extremely conformable to your body shape, and therefore very secure. This helps to avoid soreness around the stoma.

There is also a choice in the size of pouches available with some manufacturers offering standard, shorter length and mini sized pouches.

The material the pouches are made from also varies. The most modern ones are very fine, soft and discreet, with a backing that is very comfortable next to the skin.

Most manufacturers are only too happy to provide free samples for you to try (and you can also keep up with the latest developments this way).

One piece pouch with flushable liner

A recent advance in pouch technology was the development of a closed one-piece pouch FreeStyle® Vie Flushable featuring a detachable, toilet-disposable inner liner. This liner can be easily removed and conveniently flushed away.

Two-piece pouches

These pouches have a flange (or baseplate) that fits round the stoma and stays in place for several days, with separate pouches that are attached to it.

The baseplate is left in position and a new pouch is fixed to it when required. The baseplate is usually changed once or twice a week.
Stoma pouches

Aperture sizes
The size of a stoma varies in diameter and stoma pouches are available with different sized apertures or holes. Most manufacturers supply a measuring device. Find the correct sized measuring ring which fits comfortably and snugly round the stoma, without touching it or cutting in. If the stoma is irregularly shaped, it is best to cut your own pattern to fit, using the measuring device as a basis, or using pouches with printed cutting guides. Alternatively call the SecuriCare careline on 0800 585 125 for assistance. For those with limited dexterity SecuriCare offer an ultrasonic pouch cutting facility.

In the months after surgery the stoma size usually reduces slightly. Check carefully to ensure a good fit – many problems with leakage or skin soreness are caused by using a pouch with the wrong size aperture.

Wind and odour
Wind is an individual matter and can be a problem for some. It is usually most affected by what foods are eaten and when. Any wind produced has to escape, however, so many pouches have a built-in filter. This allows wind to be evacuated (thereby avoiding ‘ballooning’ of the pouch) and helps to absorb any odour from it.

If you are conscious of odour when changing your pouch, deodorant sprays such as Limone® are available on prescription.

Odour generally should not be a problem with modern pouches which have odour-proof film and filter.

Protecting your skin

The importance of cleaning carefully and gently and of taking care of the skin around the stoma to avoid soreness cannot be emphasised too much. The waste matter in the stoma pouch contains digestive juices which can harm the skin if they come into contact with it. If the skin becomes sore, it can be difficult to get it to heal and to get a good fit with the stoma pouch.

Various barrier preparations which help protect the skin are available on prescription. These include pastes, seals, powders, sprays, creams or liquids, and handy disposable wipes that can just be wiped around the area which when dry form an invisible protective skin.

Disposal bags, which are provided free of charge (to put used stoma pouches in), medical adhesive removers, belts and deodorants are also among the many stoma care accessories available.

Irrigation
There is an alternative to wearing a stoma pouch that some colostomists prefer and this is called irrigation. This involves washing out the bowel every 24 or 48 hours to remove faeces. However, only certain stomas are suitable for irrigation, so this method must be discussed with the doctor. Even if suitable, proper training by the stoma care nurse must be given first. Irrigation kits are available from some stoma care manufacturers.
Changing a stoma pouch

A colostomy pouch may be changed as often as necessary, usually after a motion has been passed. With a one-piece pouch, the whole pouch is replaced. If a two-piece appliance is used, the pouch is changed for a new one as often as required and the baseplate (flange) is usually replaced once or twice a week.

(If you use drainable pouches, the pouches may be emptied when necessary and the routine below followed when a pouch change is required. Make sure when applying a new drainable pouch that the bottom of it is securely fastened).

Changing pouches

When you are changing the pouch for a new one, make sure you have everything you need immediately to hand.

Gently and slowly supporting the skin with one hand, ease off the pouch. An adhesive remover can help to remove the flange.

The used pouch can be emptied (cut off the top of the pouch to do this), rinsed out under the flush of the lavatory pan and placed with any tissues etc into a plastic disposal bag – or wrapped in newspaper and put in an ordinary plastic bag.

NEVER FLUSH USED POUCHES DOWN THE TOILET UNLESS THEY ARE SPECIFICALLY DESIGNED WITH FLUSHABLE PARTS. DO NOT ATTEMPT TO BURN POUCHES AS THE PLASTIC GIVES OFF TOXIC FUMES WHEN BURNT.

Cleaning the stoma area

Clean gently around the stoma with plain warm water (do not rub), using soft wipes. Dry the skin thoroughly, patting dry gently with tissue or kitchen roll – again, do not rub.

If necessary, check the size of your stoma, using a measuring card. If your pouch needs adjusting, cut a hole to the required size using a pair of pouch cutting scissors. Alternatively, SecuriCare can cut your pouches to the correct size from a template.

A skin barrier may be used if required before fitting a new pouch or baseplate around the stoma.

Replacing the appliance

Remove the protective cover from the adhesive flange. It may help to warm the flange with your hands or even a hair dryer before removing the protective cover. This will help the flange to adhere better to the skin.

Fit pouch ensuring there are no creases in the adhesive. Allow a few minutes for the adhesive to mould to the skin.
Once you have recovered from your operation and are getting back to normal, having a colostomy needn’t restrict you in any way. You can do what you like, wear what you like, go back to work and generally live your usual life. Other people will not be aware, unless you tell them, that you have a colostomy.

Settling down
Do not be surprised if your stoma is active frequently in the early days. It will soon settle down to a fairly regular routine. This is helped by eating sensibly and regularly.

Food
There is no need to be on a special diet or be restricted in any way just because you have a colostomy – enjoy your food as before.

However, some foods can cause digestive problems, whether you have a stoma or not. If you want a curry, have one – but be prepared to use extra pouches the next day! Trial and error will show if there are any foods that particularly upset you, e.g. giving you excess wind, diarrhoea or constipation.

Some foods have a tendency to produce more wind or odour (e.g. beans, onions, cabbage) and some people prefer to avoid these foods in excess.

Experiment and if you think a certain food has given you problems, don’t eat it for a few weeks and then try a small portion.

Don’t forget that, like anyone else’s, your insides can just as easily be put out of routine by emotional upsets etc!

You are your own best judge of what you can eat. In all likelihood you will be able to enjoy a wide and varied diet.

Drink
Alcohol in moderation will not harm you, although large quantities of beer or lager may give you wind.

Travelling
A colostomy will not prevent you from taking trips in the U.K. or abroad by land, sea or air.

Carry a travel kit, packed in a small pouch or toilet bag, containing: clean stoma pouches, tissues, barrier wipes if used, scissors, deodorant spray if required and plastic disposal bags (plus diarrhoea medication as advised by your doctor just in case). You can then empty or change your pouch wherever there is access to a toilet and handbasin. SecuriCare provide you with a free travel pack when you place your first order.

If you are travelling by air, pack a good supply of stoma pouches and accessories in your hand luggage in case your suitcases go astray. SecuriCare provide you with a travel certificate in foreign languages explaining about colostomies. Check your travel insurance to make sure it does not preclude any pre-existing conditions or have any age limits.

For more information or a Travel Advice leaflet please call SecuriCare free on 0800 585125
Sex life
After such major surgery it is bound to take you some time to get back to normal. Don’t be in too much of a hurry about love-making, take your time.

You may feel shy at first because of the change in your body and because of the stoma pouch. Pouch covers can help, or ladies can treat themselves to some appealing underwear or nightwear (perhaps lacy cami-knickers or silk pyjamas) that can be worn during love-making.

In some cases, after the operation, there may be some local nerve damage or scar tissue that causes difficulties. Problems often resolve themselves with time and understanding. Even if some difficulties do eventually remain, there are many different ways of enjoying pleasurable sexual contact.

If you have problems, or if you are entering into a new relationship and would like advice, specialist help and counselling on the subject is readily available. Don’t wait too long: speak to your stoma care nurse or contact an organisation like Relate National Marriage Guidance (address in the back of this booklet).

Contraception
Whilst it is unlikely that having a stoma will affect fertility, it would be advisable to discuss this matter with your stoma care nurse or GP.

Pregnancy
Women with colostomies have had successful pregnancies. If you want to try for a baby, discuss the matter with your doctor or stoma care nurse.
**Problems that may arise**

**Surface bleeding from the stoma**
A slight smear of blood on the wipe when cleaning the stoma is common and no cause for alarm. It can also occur if you are too vigorous in your cleaning routine or suffer a slight knock.

**Bleeding from inside the stoma**
This is not normal. This or any change in stoma size should be reported to your doctor.

**Change in stoma colour**
If the stoma suddenly changes colour, e.g. becoming dark or blueish, check to see it is not being constricted in any way and inform your doctor at once.

**Constipation**
This can result in some obstruction, with consequent flatulence and discomfort. Extra fluids, fruit, or more fibre in the diet may help. Constipation sometimes occurs as a side effect of medication such as certain types of painkillers. If the problem is severe or happens frequently talk to your stoma care nurse or doctor.

**Diarrhoea**
Drink plenty of fluids to replace those lost. If you think that a certain food has affected you, leave it out of your diet for a few weeks and then try again. Drainable pouches can be useful while you have diarrhoea, to save changing pouches too often. If you have frequent or severe diarrhoea (or persistent vomiting) seek medical advice.

**Skin soreness**
Check the aperture size of your pouch is correct. Change your appliance only when necessary, and do so slowly and carefully. Gently ensure surrounding skin is absolutely clean and dry. Barrier wipes and creams may help. Try a pouch with better skin protection. Allergies occasionally occur – consult your doctor or stoma care nurse.

**‘Leaks’**
Leaks shouldn’t happen! Check to make sure the pouch is applied properly and that you are using pouches with the correct size aperture. Pouches vary in the degree of security offered, so try other types if you continue to have problems. Consult your stoma care nurse.

**Flatulence or gas**
This can be a problem with a colostomy. It is often aggravated by certain foods. Many colostomists discover that by juggling their diets they can manage the problem better. Some find that taking fennel tablets or eating yogurt can help. Experiment to see which foods cause it, e.g. cabbage, beans, fizzy drinks, nuts.

**No faeces going through into the pouch, associated with severe pains – seek medical advice.**

**Slow healing**
After major surgery on the rectum it is quite common for scars and wounds in this area to continue to weep for quite some time. This is quite normal, but if it happens to you and you are worried about it, talk to your nurse.

**Discharge from the Rectum (back passage)**
If your rectum was not removed, you may still pass mucus (jelly/slime) from your back passage. This is normal, but if it is frequent or causes you discomfort tell your stoma nurse or doctor. Obvious bleeding or other discharge should also be reported.

**Phantom rectum**
If you have a permanent colostomy and your rectum has been completely removed, it may feel as though you need to open your bowels in the old way, even though you cannot any longer pass motions through the anus. This feeling may last for several months after the operation, but speak to your doctor or stoma nurse if you are concerned about it.
Your questions answered

**Will people be able to tell I have a colostomy?**
The answer to that is NO – today’s stoma pouches are very slim and discreet. Wear what you like and what’s comfortable (see below for sportswear). Have you ever seen anyone who you thought looked as though they had a colostomy?

**When should I change my pouch?**
Usually when a motion has been passed. Many colostomists find that their bodies settle into a routine, passing faeces at fairly regular intervals, e.g. first thing in the morning or last thing a night.

**What about sports?**
No problem – carry on swimming, dancing, playing games, gardening or whatever you enjoy doing most. Patterned one-piece costumes disguise any slight bulges for women, while men might prefer fairly high-waisted boxer type shorts. Baggy T-shirts are great cover-ups at any time, but particularly over leotards for ladies’ keep-fit.

**Whom should I tell?**
It’s entirely up to you and is a very personal decision.

**Will odour be a problem?**
Just as with normal bowel motions, there will obviously be some odour while you are changing the pouch (deodorant sprays are available on prescription), but if you are aware of odour at any other time, check the appliance and if necessary consult the stoma care nurse. The food you eat can affect odour produced.

**Baths and showers?**
Yes, either with the pouch in place or, at times of inactivity of your stoma, without a pouch on. Water will not go into your bowel even in the bath.

**Can I take medicines?**
Yes, but remind your GP, if necessary, that you have a stoma – some tablets can go through and come out unchanged at the other end! Some drugs may alter the bowel output, i.e. constipate or loosen stool.

**Will my life insurance be affected?**
All insurance companies you deal with should be notified about your colostomy.

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Associations and support groups

**Colostomy Association**
2 London Court, East St
Reading RG1 4QL
Freephone: 0800 3284257

**ia – the Ileostomy and Internal Pouch Support Group**
Peverill House
1-5 Mill Road, Ballyclare
Co. Antrim BT39 9DR
Freephone: 0800 0184724

**CancerBACUP**
3 Bath Place,
Rivington Street
London EC2 3JR
Freephone: 0808 808000

**Urostomy Association**
18 Foxglove Avenue
Uttoxeter, Staffordshire
ST14 8UN
Telephone: 0870 7707931

**Macmillan Cancer Relief**
89 Albert Embankment
London SE1 7UQ
Freephone: 0808 8082020

**National Association for Colitis and Crohn’s Disease**
4 Beaumont House
Sutton Road, St Albans
Hertfordshire AL1 5HH
Telephone: 0845 1302233

**Royal Association for Disability and Rehabilitation (RADAR)**
12 City Forum, 250 City Rd
London EC1V 8AF
Telephone: 020 7250 3222

**NASPCS**
(National Advisory Service to Parents of Children with a Stoma)
51 Anderson Drive, Darvel
Ayrshire KA17 0DE
Telephone: 01560 322024

**Relate National Marriage Guidance**
To find your nearest Relate
Telephone: 0300 100 1234

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**Websites**

- www.colostomyassociation.org.uk
- www.cancerbacup.org.uk
- www.clinimed.co.uk
- www.bowelcanceruk.org.uk
- www.the-ia.org.uk
- www.macmillan.org.uk
- www.nacc.org.uk
- www.naspcs.co.uk
- www.radarc.org.uk
- www.relate.org.uk
- www.uagbi.org

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