

Cancer Support Helpline: 0121 704 9860

Notes for a Carer

Caring for the cancer patient
and their family



Caring for the cancer patient & their family



Contents

Introduction	3
What the OPA can offer	9
Other useful websites and publications	13
Possibilities for financial support for carers	15
Looking after their personal affairs: some considerations for carers	17
A summary of basic principles around eating post-oesophagectomy	19



The work of a carer may or may not be paid, but it requires carers to sacrifice some part of their lives selflessly to the needs of another, whether family member, relative, or complete stranger. But there is also another important aspect to caring, and that is for carers themselves to be well, and to feel supported in the work they do too. It is important to know that you, the carer, are not alone. Some professional help may be available and this booklet aims to help in identifying what is out there. There will also be others who share or have shared your situation, who can be contacted through cancer charities websites or publications, helplines or forums, or local carers groups or associations such as our own. The principal ones are listed on page 13 and 14.

The needs of those who are being cared for may be anything between slight or occasional to constant and exhausting. Their need for care may be merely temporary or last the lifetime that is left to them. The scope of caring that may be called for can be as varied as all the illnesses to be found in a medical dictionary. However, this OPA booklet is addressed principally to those caring for people who have problems arising from pre-cancerous conditions or diagnosed cancers of the oesophagus or stomach and from the treatments that are needed or have been given.

Oesophageal cancer is one of the most difficult cancers to treat, not only because a lengthy and complicated surgical operation is often the only remedy, but also because the cancer compromises the body's access to nutrition and hence its longer term health and survival. This booklet, therefore, offers carers information on what a cancer sufferer with this condition will be going through and advice on how you can prepare to care for them and what will be involved.

.....

The first inkling that something may be wrong could have been one or more of a variety of new, unexplained or worrying sensations or symptoms, such as more frequent indigestion, pain and discomfort in chest and/or stomach area, increasing difficulty in swallowing, frequent hiccups or choking, episodes of vomiting, loss of appetite and consequent weight loss. Hopefully a visit to the GP should have resulted in an urgent hospital referral to see a consultant, and an investigation via endoscopy.

If the tests confirm the possibility of oesophageal cancer and this is your partner or friend for whom you would be caring, you might expect their (and your) reaction to be shock, raising questions as to the cause, fear of the risk of cancer spreading, and anxiety over any delays in getting diagnosis and treatment. Inevitably there will be worries about the future and about the effect on their family and their ability to continue working and also, perhaps, on what might be the financial consequences of a prolonged illness.

This is the time for you, as partner and/or carer, to take the initiative in preparing questions for meetings with doctors and consultants, taking note of their answers and pursuing appointments and procedures. It is good practice to accompany them to these whenever possible, especially where courses of radiation and/or chemotherapy are prescribed before, and possibly also after, surgery. It is



advisable also to keep records of explanations given (in layman's terms, wherever possible), of tests taken and undertakings given, and follow up those results and actions. Furthermore, it would be a help at this early stage to try to gather information on resources available (advice, specialist help, financial support: see page 9 and pages 13-16), from the GP, the hospital, as well as our own website and its booklets, especially '**Guide to Life after Oesophageal/Gastric Surgery**', as this also explains what preparations may be undertaken prior to the operation. More recently, consultants have been stressing the important contribution that optimal physical and nutritional status prior to surgery can make to post-operative recovery. You can do your part to help with this.

Undergoing tests, or even a preparatory course of chemotherapy before the operation, may be a cause of anxiety, distress or discomfort such that you, as prospective carer, might take up a more assertive role in family affairs, and undertake to inform friends and relatives (or not), according to their wishes. It would be advisable at this early stage to plan what arrangements or adjustments will be needed for their **and** your own work commitments (job, family, finance) and for other dependents – children, elderly relatives, pets, etc. They may like to delegate or share some personal matters which they normally look after themselves, and/or consider assigning one or other form of Power of Attorney to you (see pages 17 and 18).

.....

In preparation for coming out of hospital after the operation, they should be given a discharge assessment. This should involve a review of facilities in the home by the hospital and/or the local authority's social services to ensure that there is the necessary equipment and space for their safe return as they may well be in severe pain, weak, nauseated, depressed and dependent, needing help in moving around, eating, washing and toileting, and sleeping. You will want to see that any extra seating, mobilizing, bathing, toileting or sleeping aids needed are in place before they return. You may have been able by then to gather information from the consultant, the Upper GI [gastro-intestinal] specialist nurse, the dietician and the physiotherapist in the hospital, on likely recovery patterns, possible complications and dangers, who and how to contact in emergencies or when concerned. Their discharge assessment should set out the dates for in-hospital follow-up appointments with all of the above specialists and advice on whether or when GP or District Nurse visits may take place. Their GP will have been informed of their discharge date. You are also entitled to a Carer's Assessment from your local authority's social services department: contacts, extra equipment you may need to deliver safely the care needed, financial assistance if you qualify (see pages 15 and 16), and eventually, possibly some respite care.



OPA Booklets



OPA Newsletter



OPA Leaflet

It would probably be helpful to introduce for them a gradual recovery regime for basic 'activities of daily living', step by step, according to their abilities and motivation. The principal effects of the operation for oesophageal or gastric cancer are likely to be changes in taste and smell sensations, loss of appetite, and consequently weight loss (which are also common reactions after any chemotherapy they may have had, which can also cause skin sensitivity). In any case their fluids and food intake may be restricted, as the effects of the surgery may take weeks or even months to heal. Initially the hospital will advise you about this. Naso-gastric tube feeding may be needed for some weeks and thereafter, the very gradual reintroduction of small amounts of solid food. In view of the effect of surgery on the size of the remaining stomach area, and the removal of an effective upper sphincter in the oesophagus, developing a habit of 'grazing' is usually recommended. This may mean anything up to six or seven small portions of food a day, as tolerated, rather than the customary three sit-down meals a day.

The OPA's booklet '**Swallowing – nutrition when it's difficult**' gives advice on foods and some recipes for a variety of suitable dishes that may help with building up strength after the weight loss that usually occurs after this surgery. Because of the changes in diet, it is important to ensure that they continue to have regular blood tests after discharge from hospital; initially 1-2 months after surgery, later approximately every 6-12 months [as a general rule dieticians have recommend FBC; Vitamin B12; Iron (Iron and iron bindings); Folate; Vitamin D; Zinc; PEI (Pancreatic enzyme insufficiency) but as every one's outcome and progress will be different, it will be for doctors to decide eventually which blood tests are needed]. These tests should then be reviewed by a dietician, Upper GI nurse or consultant. Some basic principles around eating are given on pages 19 and 20.

Longer lasting effects of an oesophagectomy may include occasional or persistent 'Dumping syndrome' (see page 19, below) after eating – a feeling of sweating, dizziness or nausea due to temporary insulin overproduction – vomiting where too much food has been taken at once, malabsorption and diarrhoea (especially

if the Vagus Nerve has been damaged during surgery), and general fatigue and depression. Sleeping patterns may be disturbed, especially as they will need to adapt to sleep at a higher angle, with extra pillows and/or a wedge, than they were used to, in order to minimise acid or bile reflux. Regaining strength and a return to life as it was before the operation may well take 12 to 18 months, and will also be influenced by the ability to manage their pain and improve their mobility.

**WE RECOMMEND THAT YOU KEEP A
DIARY OF THEIR PROGRESS!**

We recommend that you keep a brief daily diary of their progress and possibly also a food diary to be able to see which foods work and which don't. This could be kept along with your record of all appointments, prescriptions, and conversations with the medical team.



When they feel strong enough to go out, progress slowly, little by little. Always remember that going out also entails getting back. Allow for this! Maybe consider involving friends and relatives for some extra help on the first outings, and do not be afraid to ask for help from other available sources and resources. You may like to locate and join a local support group. In our experience, such meetings often provide the first and most reassuring encounters, either with others who are on the same recovery pathway and experiencing the same problems as them, or who can offer their advice from having found a way to deal with them in the past. You can contact the OPA's office for information on any existing group in your area. Eventually, when planning to eat out, get the OPA cards to hand to a waiter to ask for *smaller portions* and for *seating near toilets*, and check the suitability of menus, and the availability and location of toilets.

We also recommend that, whenever they leave the house, they should carry an abbreviated up-to-date record of their recent history, of all post-oesophageal surgical and medical interventions, of current medications, dosage frequency, any allergies, and of details of their GP and current hospital contacts, and also a note that they should *not* be laid flat.

And finally don't forget to look after yourself, too! At present the OPA holds three or four Zoom meetings every year specifically for carers, and our helpline 0121 704 9860 is open 9am to 3pm Monday to Friday, with an answerphone for out-of-hours callers. On page 9 there are details of the OPA's presence on social media and on Healthunlocked pages. You should ask to register with your GP as a carer (there is usually a form for this), and for yourself or them, if appropriate, to be registered as a 'vulnerable person'.

When your partner comes home after the operation, it is likely that your life will be taken over, especially if there are to be weeks of feeding via a tube, and everything in the care they need is likely to be new and unfamiliar. Therefore, in advance of their discharge it would be helpful to have explored with the consultant's team, and particularly with the upper GI specialist nurse and the dietician, what you should expect to have to cope with when they return home with you. Make sure you are given details of follow-up appointments, check-ups and scans, and who to contact if you have any queries or worries about their progress. Be assertive, and do not feel embarrassed to ask for help!

Sustaining your own mental health and wellbeing is important, too. You will need time to relax, to get enough sleep, to meet with friends, and opportunities to share your concerns and worries. As part of your Carer's Assessment at the hospital, you should ask for contacts for advice and extra support and, if needed, counseling or therapy for yourself. There will be times when they may be angry or depressed by problems with, or the slowness of, their recovery. This may present a challenge for you to maintain a constant calm and reassuring presence as their carer. Indeed a shared anxiety over the progress of their recovery can be stressful on you too, both physically and mentally, so either through your GP or through your local Social Services, you may ask for that extra support for you personally. Besides courses of counseling or therapy there may also be the opportunity for short respite cover or day visits to a community care centre. As well as contacting us on the OPA's helpline you can find a wealth of relevant factsheets and articles on our website. And do not overlook the excellent websites, publications and helplines of CarersUK, Macmillan, CancerResearchUK, Marie Curie and AgeUK, from whose publications we have summarized details on who is entitled to Carer's or Attendance Allowances and how to apply. These are listed on pages 15 and 16.

WHAT THE OPA CAN OFFER

- Its website: <https://www.opa.org.uk/>
- Its Helpline: <https://www.opa.org.uk/our-helpline.html>
- Booklets (detailed below): <https://opa.org.uk/product-category/opa-literature/>
- A quarterly Newsletter: <https://www.opa.org.uk/newsletters.html>
- Cards for when eating out (to ask for smaller portions, or seating near toilets):
<https://www.opa.org.uk/opa-card-for-patients-eating-out.html>
- Greetings cards
- Contacts for buddying where possible via the helpline or via the Health Unlocked (HU) Carers Forum page
- On social media: Facebook; Twitter; Instagram
<https://www.facebook.com/opa.org.uk/>
https://twitter.com/OPA_UK
<https://www.instagram.com/opacancercharity/>
- OPA pages on HealthUnlocked (HU): for Carers
<https://healthunlocked.com/oesophagus>
<https://healthunlocked.com/opa-gord>
<https://healthunlocked.com/opa-carers>
<https://healthunlocked.com/opa-palliative-care>
- OPA booklets:
 - A Guide to Life after oesophageal or gastric cancer
 - Swallowing and nutrition when it's difficult
 - Recipes for when food is a problem
 - Notes for a Carer
 - The Patients Pathway

Scan the QR code for a direct link to the OPA website.



OPA & Putnam Pillow's Bed Wedge Discount

Many people with Acid Reflux Disease have to sleep propped up. This can be difficult, but some find a wedge pillow helpful. These can be quite expensive. So, the OPA has teamed up with Putnam Pillows to provide their standard Bed Wedge. The OPA is putting £12.50 per pillow towards this partnership. Putnam's have, on top of that, agreed to a generous discount.

Putnam's also offer free delivery, or you can pay a little extra for next day delivery.

To take advantage of this offer

1. Please email the OPA first and we will give you a Discount Code – enquiries@opa.org.uk.
2. With the Discount Code, call Putnam's on 01752 345 678, email info@putnams.co.uk or visit <https://www.putnams.co.uk/collections/bed-wedge-pillows/products/bed-wedge>

Please Note:

- On the website you will be able to enter the Discount Code on the Check Out page.
- If you phone or email Putnam's with your order, there will be a small delivery charge. To get free delivery use the Putnam's website to order.

We are extremely hopeful that this initiative will help many of our members to sleep more comfortably and we are very grateful to Putnam's for their generous discount.

<https://opa.org.uk/news/bed-wedge-pillow-discount-code/>

More about Bed Wedges

Both doctors and the practitioners agree a wedge pillow is the best way to relieve the symptoms of Acid Reflux or Gastro Oesophageal Reflux Disease (GORD) and heartburn by elevating your torso to prevent acid from burning the lining of your oesophagus while you sleep.

** Subject to availability*

The Bed Wedge – Acid Reflux can be used in many ways. Place it under your pillow to sleep in a raised comfortable position which is ideal for sufferers of acid reflux and Oesophagitis.

Using a bed wedge whilst asleep to elevate your upper half can severely reduce acid reflux. Just adding extra pillows will not work because they elevate your head, not your upper torso.

It is also easier to slip off extra pillows as you sleep.

To order your free reflux awareness pack please order via our online shop <https://www.opa.org.uk/products/reflux-awareness-pack.html>

If you have reflux symptoms and need help, please get in touch with RefluxUK, who are experts in the diagnosis and treatment of reflux symptoms and have access to state of the art diagnostic tests with one of the most experienced multi-disciplinary teams in the UK. Their Doctors are all authorities in every aspect of reflux treatment. RefluxUK's website offers useful information on the causes, diagnosis and treatment of reflux.

You can phone on 0207 043 0419, email at help.myreflux@refluxuk.com or book a consultation here; <https://refluxuk.com/contact/>

Radar Key

The National Key Scheme (NKS) offers disabled people independent access to locked public toilets around the country. Toilets fitted with National Key Scheme (NKS) locks can now be found in shopping centres, pubs, cafés, department stores, bus and train stations and many other locations in most parts of the country.

This scheme, sometimes known as the RADAR Scheme, was developed because some public toilets designed for disabled people had to be locked to prevent damage and misuse. This has been countered by them being locked separately from other toilets. The NKS aims to provide disabled key holders with independent access to the toilets provided for them and increase the likelihood of the facilities being in a useable state.

The Radar key gives you independent access to over 9000 accessible toilets in the UK.

Within the scheme RADAR:

- Supplies NKS keys to disabled people who cannot, or have difficulty, getting one locally
- Maintains a list of toilets fitted with the NKS lock
- Provides general information about the scheme to individuals and providers.
RADAR does not advocate the general fitting of locks to all toilets for disabled people but does urge that the NKS is used where a lock is required.

The Radar Key can be purchased for £5.00 each, this price also includes delivery. The measurements are 102mm x 36mm (handle).

More information on how to order can be found on The Disability Rights UK website
- <https://www.disabilityrightsuk.org/shop/official-and-only-genuine-radar-key>

OTHER USEFUL WEBSITES AND PUBLICATIONS

Carersuk.org

is the charity whose sole focus is advice and support for carers. Its principal publications are:

- Looking after someone
- Being heard: a self-advocacy guide for carers

and its website has several very helpful pages, as

/upfront

/local support

/forum (for those who register as members)

/needs-assessment (similar to benefits check, for the patient)

/hospital (for when the patient is coming out of hospital)

/tips-from-carers

/managing-someone's-affairs

/break (for carers)

It also has its own Helpline and Online Forum

be.macmillan.org

This is the general portal to access all its publications and advice. Macmillan.org.uk also has its own Support Line, Online Community, and Support Groups.

Its publications include:

- Understanding oesophageal cancer
- Looking after someone with cancer: a guide for carers
- Questions for carers to ask about work and cancer
- Claiming benefits when you have cancer
- Help with the cost of cancer
- Life after cancer treatment
- Eating problems and cancer
- Working while caring for someone with cancer
- Work and cancer
- Self-employment and cancer
- Your rights at work when you are affected by cancer

Cancerresearch.org

is the principal UK charity that funds world class research on cancer. You can find out about past and current research, including many ongoing, on oesophageal and gastric cancers on its website, and at cruk.org there is a chat forum at /cancerchat, and an information service at /about-cancer.

Mariecurie.org

and its specialist Marie Curie nurses provide care, guidance and support for people living with any terminal illness, and their carers. It also has its own support line, online community and chat service. Its publications include:

- Recently diagnosed
- Living with a terminal illness
- Caring for someone
- Benefits and finances
- When someone dies

Ageuk.org.uk

Its website offers advice and publications on several issues of interest for carers, including:

- Financial support such as the Carer's Allowance, the Attendance Allowance and Carer's Credit
- Local authority assistance, and a Carer's Assessment

Carers Direct

is an NHS helpline on 0300 123 1053, for anyone needing help with their caring role, and with discovering what options are available to them. It covers ground similar to those publications and online sources found at CarersUK, Macmillan and Age UK.

Carers Trust

is a charity which "works to improve support, services and recognition for anyone living with the challenges of caring, *unpaid*, for a family member or friend ...". It offers online services, advice on possible grants, and a network of independent partners who can assist carers "to get the extra help they need to live their own lives".

Guts UK

is a charity which undertakes research on all digestive diseases (gut, liver and pancreas), and has an extensive list of patient information leaflets on digestive symptoms and conditions.

If there are children in the family, affected by the parent's cancer, extra advice is available on the websites '**Cancer.org**', '**Cancerresearchuk.org**' as well as on the Macmillan site.

POSSIBILITIES FOR FINANCIAL SUPPORT FOR CARERS

(with thanks to AgeUK, CarersUK and GOV.UK's information services)

Carer's Allowance

The eligibility rules are as follows: you need



Carer's Allowance may not be paid if you're receiving a State Pension or certain other benefits, but it's still worth claiming because you could get extra Pension Credit and/or Housing Benefit. Extra conditions would apply if you're claiming Universal Credit.

How to claim Carer's Allowance: visit the website GOV.UK to download a claim form or make a claim online, or visit the websites or seek advice from the above-named charities.

The person for whom you are caring may be entitled to claim for an Attendance Allowance

This allowance is for those of State Pension age or older, with physical or mental disability, who need help with daily living, and who are **not** already in receipt of Disability Living Allowance [DLA] or Personal Independence Payment [PIP]. The allowance is tax-free and not means-tested, and available to all who are eligible, regardless of current income or savings.

To apply, they will have needed help for at least the previous six months or, if they are terminally ill, they can make a claim straight away. If they are awarded Attendance Allowance, they may become entitled to other benefits, such as Pension Credit, Housing Benefit, or Council Tax Reduction. As with the Carers Allowance, applicants will also need to satisfy UK presence and residence requirements.

Currently, Attendance Allowance is paid at £60 a week, if they need help throughout the day *or* at night, and £89.60p if they need help both throughout the day *and* at night, as of April 2021.

AgeUK, CarersUK and GOV.UK websites offer a 'Benefits Calculator', which can give an idea of what amounts applicants may be eligible to receive.

Please note that the sums mentioned above are usually reviewed annually, in April. For updates check on the GOV.UK website.



LOOKING AFTER THEIR PERSONAL AFFAIRS: SOME CONSIDERATIONS FOR CARERS

If you are caring for someone to whom you are not related:

You should have at least one person whom you can contact at any time to share information, with their permission, about their health or recovery with their family and friends, especially if they used to live alone. And if that is the case, you need to know where to find their medical records and whom to contact in the case of an emergency.

If you are on your own while giving care, you should know who else has access to their house or might call by, and what their relationship is to the person you are caring for.

If you are caring for someone who is (temporarily or long-term) incapacitated through surgery or illness, you may want, or need, to have them set up a Power of Attorney for you, or others, to manage their affairs, if they have not already done so.

There are three types of Power of Attorney:

[In the legal jargon, the 'Donor' is the person ceding the Power, and the 'Attorney' is the person who is handed the Power. The 'Attorney' need not be a lawyer, but may be anyone over the age of 18 and who is capable of making decisions]

Whichever Power is set up, it may be advisable to give a copy to a member of their family, if they have not done so, and to their GP, bank, lawyer or solicitor, and possibly also to their social services department and benefits agency.

1. An ordinary Power of Attorney

This can be for a limited period of time of delegation (but not advised if the Donor likely to lose mental capacity because of a progressive illness). It can be set up through a solicitor, or by any Donor with assistance from the C.A.B.

See: [citizensadvice.org.uk/family/looking after people/managing affairs for someone else](http://citizensadvice.org.uk/family/looking-after-people/managing-affairs-for-someone-else).

2. A Lasting Power of Attorney

This is advisable where there is a possibility of the Donor's deteriorating mental capacity. There are two types of Lasting Powers: either for property and financial affairs, or for health and welfare, or for both. Powers will need to be registered with the Office of the Public Guardian (Address: P.O.Box 16185, Birmingham B2 2WH, tel. 0300 456 0300) for a fee, but only after any other people implicated in, or affected by, this Lasting Power have been informed. There are standard forms for both these types.

3. Enduring Power of Attorney

It is no longer possible to register an Enduring Power, but those registered before 1 October 2007 are still valid. There are some exceptions to Enduring Powers registered up till April 2017: see C.A.B. website above.

A SUMMARY OF BASIC PRINCIPLES AROUND EATING POST-OESOPHAGECTOMY

For more details see the OPA booklets 'Swallowing and nutrition when it's difficult', and 'Recipes for when food is a problem'

- Eat regularly (usually small amounts, akin to 'grazing', even if you are not hungry)
- Eat what you can tolerate (even if not exactly healthy!)
- Chew well (restrict eating bread, at least initially)
- Favour dairy foods, if tolerated
- Avoid take-aways!
- Use plastic cutlery if metal has an unpleasant taste
- Avoid eating late at night
- Sleep upright, or at least with a bed wedge

A common problem: Dumping Syndrome (advice drawn from Cleveland Clinic website)

Effects/sensation of Dumping Syndrome can be:

- Nausea and vomiting
- Abdominal cramps
- Diarrhoea
- Flushing/sweating
- Dizziness
- Raised pulse

Recommended steps:

- Increase intake of protein and fibre (wholegrain foods, meat and fish, eggs, nuts)
- Take small meals more frequently
- Avoid drinking fluids 30 minutes before, and 30 minutes after meals
- Avoid simple sugars in food and drinks
- Possibly avoid lactose, i.e. in dairy products
- Increase thickness of foods and drinks
- Replace minerals after excessive diarrhoea, but avoid excessive use of loperamide to counteract it

Advice on reducing excessive bile secretion (and vomiting): avoid or minimise

- Butter, margarine, or mayonnaise
- Fried or breaded foods
- Pastries, especially flaky pastry
- Sausage, bacon, and processed meats
- Full fat dairy produce

(note that intake of some fats is essential, therefore substitute the above with avocados, oily fish, nuts, etc.)

The above suggestions are for trial and error because no two people who have this operation react in the same way when it comes to eating.

“ Being a carer is about every single day, sometimes about all the hours in every day. It’s about routine, the endless repetition of things, of always having someone else’s needs at the forefront of your mind: medication, meals, laundry, a doctor’s appointment or a more comfortable position in which to sit. It is about having a parallel life running alongside your own. However much you do, it never feels enough. But though often remorseless and exhausting, it’s important also to celebrate the moments of caring that are rewarding and fulfilling, that are fun, joyous. It’s important to look for hope.

Kate Mosse

Author of *An Extra Pair of Hands: A story of caring, ageing and everyday acts of love*, writing for *Saga Magazine*

”

ABOUT US

The Oesophageal Patients Association (OPA) is an independent registered charity formed in 1985 when a few former oesophageal cancer patients met and found tremendous reassurance in sharing experiences. Since then, we have helped thousands of patients, carers and their families. The friends and users of the OPA are primarily patients who have experienced oesophageal or gastric difficulties, not forgetting the hard work of their carers of course and the support of their families, friends and our excellent Health Care Professionals. We produce many thousands of our booklets and leaflets as a valuable reference, to many organisations, patients, carers and their families.

The Charity is represented on various committees involved with the management of upper GI cancers and research into new treatments. Patient involvement is increasingly recognised as a valuable input to the thinking and documentation on such matters.

WHAT WE OFFER

Our objectives are to help patients, carers and their families to cope with any difficulties arising as a result of treatment, giving support and encouraging them to achieve a good quality of life. This is done by providing information booklets and leaflets on matters of concern, a telephone support line, arranging patient support meetings around the UK and, where possible, visiting patients in hospital or making contact during their convalescence.

We make no charge to patients or their families for any support and advice provided. The OPA can only maintain its vital service through Trust donations and other fundraising activities generated by the community it serves.

It costs the OPA substantial funds to keep vital services running, providing advice, support and practical help.

We produce many thousands of our booklets and leaflets as a valuable reference to patients, carers and their families, as well as many organisations and all of this is supplied free of charge, paid for by the OPA. We would be grateful for any donations you could make so we can continue to help those who need it – <https://opa.org.uk/donations/>

Support Nationwide

The OPA has led the fight against oesophageal and gastric cancers for over 30 years. Our purpose is to support patients, their families and carers and raise awareness of these cancers and their prevention. Whatever stage you're at the OPA is here to help you.

Group Support (virtual since March 2020 due to COVID-19)

By sharing experiences and discussing our issues and problems, we are often able to help each other overcome areas of common concern.

Support meetings: These are held around the UK throughout the year, inevitably most patients attending these meetings have had, or are going to have surgery. The OPA's aim is to help new patients, families and carers to cope with difficulties arising as a result of treatment, giving support and encouraging patients to achieve a good quality of life.

Our patient support meetings provide the opportunity for patients to meet former patients, carers, some of whom are leading relatively normal lives.

One to One Support

We also offer patients the opportunity to be able to speak directly to a former patient and gain reassurance that life can again be very good.

From personal experience, we know that the first few weeks and months before and after treatment can be challenging.

Most patients find it helpful and encouraging to talk to someone who has experienced similar symptoms and has undergone the same course(s) of treatment. Our volunteers (all of whom are current or former patients themselves) are on hand and willing to offer you support, encouragement and reassurance.

Whilst The OPA does not offer counselling or medical advice, we offer general guidance and suggestions based on our own experiences. From questions to ask your GP, to tips on what to eat... plus a lot more.

We will be happy to put you in touch with someone local to talk to via a Zoom appointment or over the telephone. Please contact our Awareness and Cancer Support Helpline on:- 0121 704 9860 or by email: awareness@opa.org.uk or enquiries@opa.org.uk

Newsletters

Sign up for our twice yearly Newsletter with articles of interest and latest news of treatments. Scroll down to the bottom of this page to register.

MEDICAL SUPPORT

The OPA is an independent registered charity which works with specialist hospitals and medical teams around the UK where oesophageal and gastric problems are regularly treated. The teams involving Upper Gastrointestinal surgeons, thoracic surgeons, gastroenterologists, oncologists, dieticians and physiotherapists have extensive experience of treatments and provide continual support and advice to the OPA.

Cancer Support Helpline: 0121 704 9860

HOW YOU CAN HELP

We receive no government funding, nor do we make any charge to patients carers or their families for any support and advice provided. The OPA can only maintain its vital service through donations and other fundraising activities generated by the community it serves.

If you can support the work of the OPA at this time we would be indebted to you.

Cheques should be made payable to The OPA and sent to:
**Fundraising Dept. The OPA, 6 & 7 Umberslade Business Centre,
Pound House Lane, Hockley Heath, Solihull B94 5DF.**

YOUR LEGACY COULD MAKE A DIFFERENCE



A message from our patron Fiona Wade:

“ Your legacy will help to save the lives of future generations. Please consider making a gift in your Will to The OPA and help us to continue our fight against oesophageal and gastric cancers.

I lost my Father to oesophageal cancer. He was such an amazing person, the best father I could ever wish for and it was so sad and shocking when he was diagnosed. I had never heard of his type of cancer before and I always feel to this day that if we had been more aware of oesophageal cancer or reflux disease then, for sure, earlier diagnosis would have made a huge difference and maybe saved his life.

Early diagnosis by spreading awareness is absolutely key in saving lives from this cancer. So please help us carry on doing all we can to make people more aware and help us to save lives and to support every single patient who needs our help. Thank you.”

You can support The OPA by making a gift in your Will; one of the most effective ways to help ensure that our fight against oesophageal and gastric cancers continues our mission to save the lives of future generations.

https://opa.org.uk/wp-content/uploads/2021/02/20200901_legacy_leaflet_dl_6pp_-_final1.pdf

HOW YOUR GIFT WILL HELP

Your gift will help the Oesophageal Patients Association (OPA) to encourage seeking early diagnosis and will assist patients who are facing or recovering from an operation for one of the most unpleasant, life-changing and rapidly increasing cancers.

Early symptoms may only show as heartburn or indigestion, often resulting in late referral and diagnosis. Treatment by surgery is extremely complex with long operations that often involve restructuring the digestive organs in the chest, which is a traumatic procedure.

We can continue to give medically informed support to patients, carers & families through:

- Our cancer support helpline
- Online information and support
- Medically approved high quality information booklets & leaflets
- UK wide network of patient support groups & OPA buddies

Your gift will also help us to continue to work with the NHS to improve cancer treatment and outcomes and to continue our support across the UK.

Making your Gift

The OPA is an independent registered charity. We receive no government support and depend entirely on public support.

The Chairman and Trustees of The OPA will ensure that legacies are used to the greatest advantage and your gift will not be used for administration costs.

If you would like further information, please complete your details below and return to this address: The OPA, 6 & 7 Umberslade Business Centre, Pound House Lane, Hockley Heath, Solihull B94 5DF.

I am considering leaving a legacy to The Oesophageal Patients Association - please send me more information about your work

I have made a gift in my Will to The Oesophageal Patients Association - please keep me informed about news and events

Do you want to receive communications from the OPA?

You will receive our printed bi-yearly newsletter and e-news with helpful features and the latest oesophageal and gastric cancer news. You will also receive news of our local patient support meetings and events should you wish to attend.

All of this at no cost to you!

<https://opa.org.uk/register/>

I would love to make a donation



I am pleased to send a donation of £ _____ Please tick here if this is to be treated as a Gift Aid donation.

Title: (Mr/Mrs/Dr etc.) _____ Name: _____

Address: _____

Tel: _____ Email: _____

Signature: _____ Date: ____ / ____ / ____

For online donations – Account number: 51354981 Sort Code: 40-42-12

For Standing Order Donations

By bank transfer

Recipient bank: HSBC Bank

Sort Code: 40 - 42 - 12

Account Number: 02301636

To make an online donation visit:

<https://www.opa.org.uk/donations.html>

By regular Standing Order payment –

Sort Code: 40-42-12

Account Number: 51354981

I wish to make regular donations to the Oesophageal Patients Association of (tick appropriate box)

£2 £5 £10 £25 £100, or other amount: _____

Please state amount in words:

every (tick appropriate box) Week Month Year starting on ____ / ____ / ____ until further notice.

Your bank details

To: (insert name and address of your bank) _____

Sort Code: ____-____-____ Account Number: _____

Boost your donation by 25p of Gift Aid for every £1 you donate

Gift Aid is reclaimed by the charity from the tax you pay for the current tax year. Your address is needed to identify you as a current UK taxpayer.

In order to Gift Aid your donation you must tick the box below:

I want to Gift Aid my donation of £ _____ and any donations I make in the future or have made in the past 4 years to the OPA.

I am a UK taxpayer and understand that if I pay less income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay.

Your Details

Title: (Mr/Mrs/Dr etc.) _____ Name: _____

Address: _____

Tel: _____ Email: _____

Signature: _____ Date: ____ / ____ / ____

Please send this form to: Fundraising Dept. The OPA, 6 & 7 Umberslade Business Centre, Pound House Lane, Hockley Heath, Solihull B94 5DF. Or email to: enquiries@opa.org.uk

For further information please contact The OPA on 0121 704 9860 or email charity@opa.org.uk.

Ways You Can Donate



Online Donations

Online donations make things really simple, no need for you to collect money in person or worry about banking cheques etc. Online donations are becoming more popular, many donation portals also allow you to log in and check how your fundraising is going and check your progress.

The OPA accept payments via Paypal, bank transfer, Just Giving, Virgin Money Giving, debit or credit card or donations via mobile.



Text Donations

One-off Text Giving

Text **HELPOPA 3** to 70450 to donate £3.

Simply change the amount e.g. **5, 10 or 20 to donate more.**

Regular Text Giving

Text **DONATEOPA 3** to 70450 to donate £3 a month.

Simply change the amount e.g. **5, 10 or 20 to donate more.**



Postal Donations

You can now make a single donation by cheque or set up a regular payment via standing order. Please make cheques payable to the **“Oesophageal Patients Association”** (or **“OPA”**) or download our Standing Order form (PDF).

Please address your donation to:

6 & 7, Umberslade Business Centre, Pound House Lane,
Hockley Heath, Solihull B94 5DF



PayPal

You can make a donation to the OPA via our paypal page - see www.paypal.com/donate/?cmd=_s-xclick&hosted_button_id=X2FRXGH7FTGCC.



Bank Transfer

Account Payee: OPA Bank: HSBC Bank.

Sort Code: 40-42-12. Account Number: 02301636



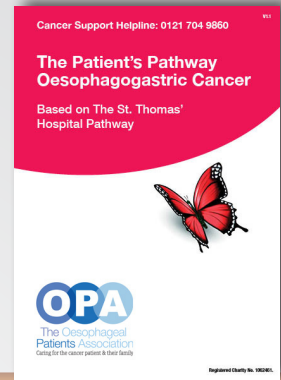
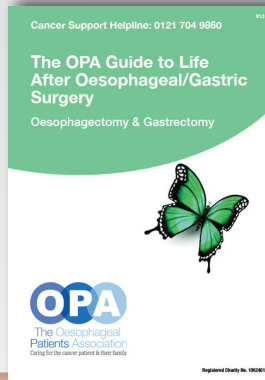
Just Giving

Visit the OPA's Just Giving page at

<https://www.justgiving.com/oesophagealpatientsassociation>

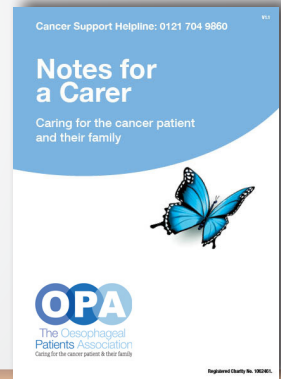
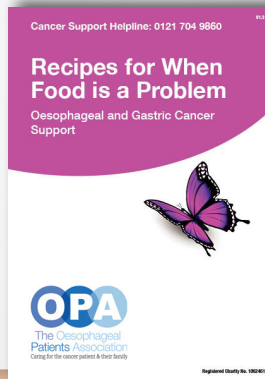
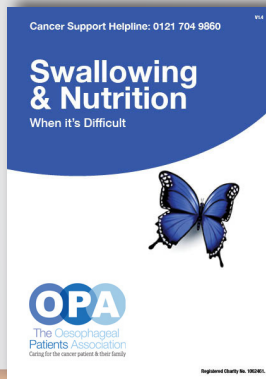
Publications from the OPA.

We are here to help those with or affected by Oesophageal and Gastric Cancer, here are some of our helpful booklets, they are free and can be posted or downloaded from our website.



A Guide to Life After Oesophageal/Gastric Surgery - Oesophagectomy & Gastrectomy
(Informative guide for Oesophageal & Gastric patients following surgery)

The Patients Pathway - Oesophagogastric Cancer
(Patients guide following diagnosis based on the St. Thomas' Hospital Pathway)



Swallowing & Nutrition - when it's difficult
(For those not having an operation but perhaps having a stent inserted or other treatments)

Recipes for When Food is a Problem
(Recipe book for patients post surgery/treatment)

Notes for a Carer
(Informative guide for carers of Oesophageal & Gastric patients following diagnosis)

These publications are available to patients and medical staff on request. There is no charge to individuals and no membership subscription. The OPA is supported entirely by donations.

Reviewed by Ewen Griffiths, MD FRCS Consultant Upper GI Surgeon, and Laura Nicholson, Upper GI Dietitian at University Hospitals Birmingham NHS & Professor Janusz Jankowski MBChB MSc MD PhD PGCE PGCM AGAF FACG FRCP SFHEA 2019.



Caring for the cancer patient & their family



Cancer Support Helpline Tel: 0121 704 9860

9.00am - 3.00pm Monday to Friday.

(Answerphone for out of hours callers)

Email: enquiries@opa.org.uk

Web: www.opa.org.uk

This booklet is published by the OPA relying solely on donations.

If you have found this book useful and would like to make a donation to the OPA, please visit: www.opa.org.uk/donations.html

Copyright © Oesophageal Patients Association 2017-2019.

Published 2017. Revised Sept 2019. All rights reserved.

Charity No. 1062461.