

WHAT PEOPLE SAY...

The Swallows

Head & Neck Cancer Support Group
Registered Charity Number: 1149794



www.theswallows.org.uk



WHERE DO I BEGIN?



Where do I begin... I cannot thank Swallows enough for the support I have received as a caregiver for my husband from the very beginning of his journey, not long after diagnosis. My world had been turned upside down and I felt so alone and unable to share my worries with my husband. I didn't want to burden him. Both Chris and his wife have been a constant source of support whenever I have needed it. Sharing their experiences and giving reassuring advice and tips to help get through the treatment along with the never ending side effects which were ever changing. My calls were always answered whenever I felt overwhelmed and, although I have a supportive network of family and friends, it was so reassuring to speak to someone who had been on a similar journey and could just listen to me and put my mind at rest.

This journey has been a rollercoaster but with the support of Swallows it has helped iron out the bumps along the way!

I know we still have a long road ahead of us but with Swallows support I know we will get there.

This group has been invaluable and I really don't know how I would have coped without them and the shared WhatsApp advice along with the care boxes we received. I will never be able to thank Chris and Amanda and Swallows enough for the difference they have made and would like to send our sincere gratitude for everything.

We will be eternally grateful.

It's definitely a 5 star ★ award from us.

Take care

Daphene Clarke



THE CHARITY IS WONDERFUL, BOTH CHRIS AND SHARON ARE AMAZING



I first had contact with The Swallows Charity after seeking advice for my mum who has swallowing issues following radiotherapy. Chris was so helpful and supportive, sending out a support box and advising on different mouth washes and mouth sprays.

I have continued to have links with the charity, not only on a personal level but also a professional level as I work with Head and Neck cancer patients.

The charity is wonderful, both Chris and Sharon are amazing - providing support and advice as well as increasing public awareness of Head and Neck Cancer. The annual conference along with their monthly support meetings are so beneficial for so many survivors. I wouldn't hesitate to signpost family, friends or my patients to this charity, and I would definitely give them 5 stars



Debbie Richardson

Senior Physiotherapy Support Worker

I will be forever grateful to my dentist and the consultant and his team who operated and looked after me. The NHS is truly wonderful.

I have a life changing condition but I am thankful for every day. I know how fortunate it was that the cancer was caught early. Like everyone, I really do worry about the future. All sorts of thoughts occupy my mind at certain times of the day and night, these are a natural part of the future, but I hope to continue with a positive frame of mind and live and enjoy each day as best I can. I have very recently been diagnosed with pre cancer and so here we go again on the journey. I am so glad I can share my thoughts and feelings with the Swallows Family on the Zoom meetings for moral support. Family and friends are lovely but they do not understand as fellow cancer sufferers (for want of a better word) do, so long live the Swallows Charity.

Susan Lee

I JUST WANTED TO SAY A GREAT BIG THANK YOU FOR YOUR GIFT BOX

My name is Karen Yearn and you recently, and very kindly, sent me a box of goodies. I just wanted to say a 'Great Big Thank You' for your gift box. The contents are helping me with my mouth and throat after 4 weeks of radiotherapy to my neck. It is overwhelming, but the kindness of people and their wanting to help others is heartwarming. I've had a tough 18 months, firstly with my mum being diagnosed with Lymphoma, then myself with the same cancer 10 months later. Unfortunately my chemotherapy didn't erase all my cancer, hence the radiotherapy.

I have seen you have a Justgiving page, I shall be making a donation on there, so you can carry on sending out these wonderful boxes which DO make a big difference to those in need. Your kindness and thoughtfulness mean more than I can express.

Thank You again
Karen Yearn

The Swallows Head and Neck Charity is one of the most valuable resources us head and neck cancer patients have.

From running an informative and innovative annual conference to being available for help and advice on a 24 hour basis, they have wonderfully filled a void in cancer care. They run regular meetings and have particularly good caregiver support. Caregiver support is a hugely neglected aspect of care.

They provide support boxes full of all sorts of mouth goodies. I received one early in my recovery and found everything useful.

I volunteer for Macmillan and I frequently signpost people to the Swallows.

Dani Akrigg





THE SWALLOWS GROUP IS AN INDISPENSABLE SUPPORT

I have known Chris since his personal involvement with cancer, followed by the creation and incredible growth of the Swallows Charity. His business experience has driven it on to be, in my opinion, one of the best resources, not just nationally, but internationally for people with Head and Neck Cancer. My charity will always refer people we find affected by this terrible disease to Chris and his team. In many aspects I believe they go above and beyond a lot that the NHS can do.

Collaboration is key to what they do and they have many incredible partnerships. Chris has worked hard in recent years with the sustainability issue of a smaller charity, and has a wonderful team around him now. I'm proud to call him a friend and work with him to help more people affected by cancer.

This sector needs more organisations like this. Without doubt I would give them 5*

If I can help with anything more, please don't hesitate to get in touch.

Very best, Chris Lewis

Dear Chris,

The Swallows group is an indispensable support to people who have suffered with the treatment and recovery of Head and Neck cancer. The organisation of local groups makes this support accessible and personal, especially as regular face-to-face contact makes possible opportunities to meet fellow sufferers at different stages of recovery and share our different experiences. Without this mutually supportive Swallows cancer group I am convinced recovery rates will be reduced. We need both emotional and physical support. Swallows is there for us.

I give it 5 Stars.

Yours sincerely,

David Pickton

Oropharyngeal Squamous Cell Carcinoma sufferer





I HAVE WATCHED THE UK BASED ORGANISATION GROW FROM MY AUSTRALIAN PERSPECTIVE AND AM IN AWE

I've known of Chris Curtis and the Swallows Group since mid 2017 when I was diagnosed with a rare oral cancer.

Back then, I sought information on line and found The Swallows Group and saw Chris' story on line as well as his progress after cancer. The person I also knew from then was Marty Doyle, a former head and neck cancer survivor and an Australian pioneer in getting the head and neck cancer awareness stories out there.

Since then, I have watched the UK based organisation grow from my Australian perspective and am in awe of some of the ways this group, under Chris' lead, has grown.

Head and Neck cancer is growing as a cancer world wide and it can seem like there is little information out there generally which is why I see The Swallows Group doing all it can in the UK and sharing its knowledge globally.

After my surgeries, for removal of the cancer in my upper mouth, and reconstruction, I began volunteer work as an Ambassador with the Australian Charity Group called Beyond Five, now Head and Neck Cancer Australia.

I've now retired from my voluntary role after 5 years. I continue to share head and neck cancer awareness via my blog and on social media.

I wish Chris Curtis and the Swallows Group all the best in their future endeavours and rate them as a five star charitable organisation out there to help those like me, diagnosed with head and neck cancer.

Denyse Whelan B.Ed. M.Ed.
www.denysewhelan.com.au

**THE MEETING IS SUCH A
REFRESHING EXPERIENCE,
BRINGING TOGETHER A
COMMUNITY TO BETTER
UNDERSTAND HEAD AND NECK
CANCERS**

Dear Chris

I wanted to highlight all the amazing work that The Swallows Head and Neck Cancer Group have done over the past couple of years. I have been involved in attending and presenting at their annual conference which brings together patients, advocates, industry, biopharma, scientists and clinicians who're all tackling head and neck cancer. The meeting is such a refreshing experience bringing together a community to better understand head and neck cancers. In Australia, we often use The Swallows as a shining example of an effective, and much needed, Cancer Support Group. We have also referred many patients to this group.

Best wishes
Arutha Kulasinghe

Arutha Kulasinghe BSc Hons, PhD
Clinical-oMx Group Leader, Frazer Institute, The University of Queensland (UQ),
Founding Scientific Director, Queensland Spatial Biology Centre (QSBC),
Senior Research Fellow, Institute of Molecular Biosciences, The University of Queensland (UQ),
Senior Lecturer, Centre for Genomics and Personalised Healthcare, Queensland University of Technology (QUT),
Translational Research Institute, Office 5019, Level 5,
37 Kent Street, Woolloongabba, Qld 4102, Australia.

**I WAS VERY FORTUNATE TO FIND
SWALLOWS - WITHOUT CHRIS AND
THE TEAM I WOULD HAVE BEEN
LOST IN THE WILDERNESS**

Being diagnosed at 56 years old with stage 4 cancer is not something I had planned in my years heading to retirement. When the news comes you feel alone and lost, no matter who is there.

The search starts to find as much information as you can and any help out there that is not directly NHS.

I was very fortunate to find Swallows. Without Chris and the team I would have been lost in the wilderness. They have supported me in every way possible, and whenever I have needed them they are there. They have also shown me the ways to shine a light for others.

One instance was when I had finished surgery and was now going into radio and chemotherapy. They were there again, delivering care packages to help my next stage.

I cannot thank them enough, or speak highly enough of the team.

Regards

Jon Organ survivor

The Swallows organization is absolutely vital to those going through treatment for head and neck cancer. As a stage 4 tongue cancer survivor, I know first hand how important their products and services can be to patients struggling with side effects.

Neil Pilla
Survivor



PATIENT ADVOCACY IS ONE THING AND YOU HAVE PROVIDED THAT IN FULL

I just wanted to touch base and commend you and The Swallows Head & Neck Support Group for an outstanding job of merging clinician's expertise with the patient experience in a practical and relevant platform. I have seen your organization grow from its initial inception to the powerhouse it is today! What a transformative growth from the desire of one man, YOU, to simply meet a need for those experiencing head and neck cancer including diagnosis and treatment and the unfortunate side effects. Patient advocacy is one thing and you have provided that in full, but you have continued to grow, evolve and adapt to the ever changing public health landscape. You realize that having multiple resources and support all in one site made it easier for those navigating a tremendously challenging diagnosis and treatment. In this day and age of misinformation, disinformation and monetization you stand for something authentic, genuine and useful. Your 24/7 hotline, monthly live and virtual meetings,

The Swallows Annual Conference of experts and community forum are only some of the valuable services you provide. I, for one, am proud to know you and am so grateful that you followed your vision with a legit plan of action!

Keep up the excellent work and please do not hesitate to reach out if I can do anything for you!

Kind regards,

Teresa Biber LoMonte, M.S.CCC-SLP

Creator of The Biber Protocol®

International Dysphagia and Electrotherapy Consultant
"Putting the Care back in Healthcare"

WHAT THE SWALLOWS SUPPORT GROUP HAS DONE FOR ME AND MY WIFE

My overview of all The Swallows Support Group has done for me and my wife.

Since I was diagnosed The Swallows Support Group has been invaluable, from the welcome packs for myself and the caregiver to the group meetings you arrange monthly to the 24hr phone support.

The welcome packs not only gave me an insight into what to expect but the mouth gels, mints, and other bits were a welcome addition as I would never have known about them.

When we received the packs, I immediately felt someone not only knows I'm in a scary place but has done the journey and created a support group and considered the caregiver as well.

I had it quite rough in the beginning as well as after. My wife Daphene spoke to you, and you gave her reassuring words to give to me regarding what to expect, what to do etc. Thank you.

I cannot thank you guys enough. The people I met on the oncology ward also spoke how you guys have been there for them.

Thank you Swallows, thank you Amanda ❤️

I would rate Swallows 5 ★★★★★

With love

Leyland Clarke



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Wednesday 4th October 2023

RE: The Swallows Head and Neck Cancer

Dear Sir/Madam,

I am a scientific research group leader at the Institute for Regeneration and Repair at the University of Edinburgh, where my research group are working to find strategies to regenerate the salivary glands after off-target irradiation damage during radiotherapy for head and neck cancer (HNC). HNC is **the 8th most common cancer in the UK** with an incidence of 43/100,000. Over the last decade, HNC incidence rates have increased by ~1/6 (**16%**) in the UK (figures from Cancer Research UK). While the rate of survival has improved in recent years, the gruelling treatment regimes significantly impact survivor quality of life. Furthermore, as HPV+ HNC becomes more common, the age of diagnosis has gotten progressively lower, meaning that survivors are generally living for many more years than previously expected.

While this is very positive, I have witnessed, first hand, the effect that this life-saving treatment has on survivor quality-life of life. Treatment can cause severe fatigue; an inability to eat, chew and swallow; difficulties sleeping; and can impact relationships, the ability to socialise and can often mean survivors can no longer work.

I work closely with The Swallows Head & Neck Cancer Support Group, and they provide an incredible support, informative and networking service to patients, survivors and their families. They rely entirely on fundraising and donations, but could provide so much more if they had the resource to do so.

Thus, I wholeheartedly support The Swallows in receiving more significant funding.

Yours sincerely,



Dr. Elaine Emmerson
RCUK/UKRI Innovation Fellow & Chancellor's Fellow
The Centre for Regenerative Medicine, Institute for Regeneration and Repair
The University of Edinburgh